



**PERSONS WITH MENTAL  
RETARDATION AND  
RELATED CONDITIONS IN  
MENTAL RETARDATION  
FACILITIES:  
SELECTED FINDINGS FROM THE  
1987 NATIONAL MEDICAL  
EXPENDITURE SURVEY**

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**U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy**

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EXPENDITURE SURVEY**

K. Charlie Lakin  
Bradley K. Hill  
Tsuey-Hwa Chen  
Susan A. Stephens

University of Minnesota  
Center for Residential and Community Services

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## **Abstract**

This report presents selected statistics gathered on residential facilities designated as mental retardation facilities and on the residents of those facilities as part of the Institutional Population Component of the 1987 National Medical Expenditure Survey (NMES). The report is divided into 4 parts. Part 1 presents general background to and overview of the National Medical Expenditure Survey, and of the data available from it. It discusses previous efforts to conduct census or sampling surveys representing all persons in residing in mental retardation facilities. It briefly summarizes the design of the NMES Institutional Population Component, limitations evident within its sample frame, and some of the cautions that derive from these limitations. Part 2 presents statistics on the characteristics of mental retardation facilities and of the residents of those facilities from the National Medical Expenditure Survey. The data analyzed and reported come from the NMES Baseline (resident) and Facility Questionnaires. Data are summarized according to three recurring groupings of facilities: (1) by operation (private for-profit, private nonprofit, and public) and size (15 or fewer and 16 or more residents); (2) by ICF-MR certification (ICF-MR certified or not certified) and size (15 or fewer and 16 or more residents); and (3) by size alone (1-6, 7-15, 16-75, 76-299, 300-799, and 800 or more residents). A brief discussion is provided on the findings presented in each of the 32 tables included in this summary. Part 3 briefly examines an alternative method of using the population estimates from NMES that may compensate for certain of the limitations in the NMES sample frame and resulting underestimation of the population of small mental retardation facilities to yield a somewhat more realistic picture of mental retardation facilities and their residents in 1987. The report ends with a brief "Summary and Conclusions" regarding the NMES study and the relevance of its findings to current issues in residential services for persons with mental retardation and related conditions.

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# **PART 1: BACKGROUND AND OVERVIEW**

For over a century now the United States government has itself collected and/or has contracted with other agencies to collect basic information on the populations residing in institutions<sup>1</sup> for persons with mental retardation and related conditions. Government attempts to enumerate persons in mental retardation facilities began as part of a notably more ambitious project. In the decennial censuses of 1850 through 1890 a serious, although apparently unsuccessful, attempt was made to count the total number of people in the United States who were among the “detective [i.e., mentally, physically or sensorially impaired], dependent, and delinquent classes.” However, it was soon reasonably clear to those directing the special census that because of reluctance of families to report stigmatizing conditions, lack of operational definitions and low public familiarity with specific disorders, the entire effort could at best be called imprecise. Still, the 1880 and subsequent census did show apparent success in obtaining statistics on “inmates of institutions,” including 40,942 people in institutions for “the insane,” 2,429 people in institutions for “idiots,” 2,158 people in institutions for “the blind,” 5,267 people in institutions for “deaf-mutes,” and 66,203 people in almshouses (U.S. Census Bureau, 1888).

In 1900 no attempt was made to do a census of “special classes” in conjunction with the national census, and in 1902 further attempts to conduct such enumerations were specifically limited by Congress to persons residing in institutional settings: “The statistics of special classes ... shall be restricted to institutions containing such classes (House Reports, 1902, p. 48). Studies of the institutionalized populations of persons with mental retardation and related conditions have continued until the present day. From early housing of the data collection efforts with the Bureau of the Census, where they remained through 1946, federal efforts to conduct or fund research on institutional and special settings populations have been passed to a range of agencies focused on specific populations (e.g., the National Institute on Mental Health), or specific programs (e.g., the Health Care Financing Administration), or agencies with more general topical or data gathering responsibilities (e.g., the National Center on Health Statistics, National Center on Health Services Research, or periodically the U.S. Bureau of the Census). This disjointed responsibility, in which statistical agencies have focused primarily on their own programs, their own interests, and their own populations, all in their own way, has led to particularly significant limitations in the overall coverage, comprehensiveness, coordination and quality of statistics on persons with mental retardation and related conditions in institutional or alternative care facilities, because no major federal program or statistical agency has this group as its primary interest. The 1987 National Medical Expenditure Survey, with its Institutional Population Component including a large sample of persons with mental retardation and related conditions in supervised care arrangements represented a significant step in overcoming such problems.

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<sup>1</sup> “Institution” in this report, in congruence with its use in the “Institutional Population Component” of the National Medical Expenditure Survey which is the basis for this report, is defined here as a place where people live with supervision, care and/or treatment from people other than family members for conditions causing functional limitations.

## **Recent Research**

Despite the many limitations that can be noted about the federal commitment to data gathering on persons with mental retardation and related conditions in institutional settings, there have been a number of useful recent sources of national statistics, all conducted or substantially supported by Federal government agencies. The most significant and recent of these studies are reviewed below.

### **Census Surveys**

Since 1980 three censuses, or complete enumerations, have attempted to include all institutional and other residential settings for persons with mental retardation and related conditions. These were the Decennial Census of Population and Housing in 1980, the National Census of Residential Facilities (NCRF) for people with mental retardation in 1982 (Lakin, Hill & Bruininks, 1985), and the Inventory of Long-Term Care Places (ILTCP) in 1986 (Sirrocco, 1989). These are briefly discussed below.

Each ten years the Bureau of the Census conducts the Census on the entire population, regardless of residential setting, and publishes data on those living in places that it categorizes as institutions or noninstitutional group quarters. Specific questions vary somewhat from census to census, but always include demographic and basic housing items. Health questions, if included, appear in the "long" version of the census form, which only a sample of the population is asked to complete. A complete enumeration of persons in all types of institutions and special settings is conducted with each Decennial Census of Population and Housing. However, the purpose of the Decennial Census is reapportionment and statistics covering the entire population. Accordingly, the attempts on the part of the Bureau of the Census to systematically classify the types of facilities have been less thorough than the actual population count. In all the 1980 Census identified almost 50,700 institutions with about 2.5 million residents. The largest single category of both facilities and residents was the "home for the aged" grouping, which includes nursing homes and personal care facilities for elderly persons. The category "mental hospitals and residential treatment centers" included about a quarter of a million people. The count in the 1980 Census of facilities for mental handicapped, individuals was 5,410 facilities and 149,421 residents. NCRF surveys of facilities for persons with mental retardation undertaken three years before and two years after the 1980 Census (i.e., in 1977 and 1982) found 11,025 and 15,633 facilities, respectively, and 247,796 and 243,669 residents with mental retardation, respectively (Lakin, Hill, & Bruininks, 1985). While the frequent small size and "typical household" nature of many group homes for persons with mental retardation may have contributed to this discrepancy, they cannot fully account for it. As noted the 1980 Census identified 5,410 "homes and schools for the mentally handicapped." In the 1982 mail census there were identified 5,164 facilities of 7 or more residents, and even this subset of mental retardation facilities in 1982 had populations that outnumbered the 1980 Census facility populations by 210,481 to 149,421. While the number of "facilities" for persons with mental retardation that are of a "typical household" size and/or nature (i.e., foster family care models)

may have contributed to undercounting mental retardation facilities in the U.S. Census, other factors are obviously involved. One such factor could possibly be that many mental retardation facilities are misclassified as mental health facilities, nursing homes, or homes for persons with physical handicaps, although there is no evidence of the greater than expected number of these other facilities which would be expected to result from such misclassification.

The other two general census surveys of residential settings for persons with mental retardation and related conditions conducted during the 1980s (the 1982 NCRF and the 1986 ILTCP) are discussed in some detail in the next section of this paper which describes the methodology and limitations of the Institutional Population Component of the 1987 National Medical Expenditure Survey. Therefore, they are only briefly mentioned here. The University of Minnesota conducted a census type survey of all state licensed, contracted or operated residential facilities for people with mental retardation in the U.S. as of June 30, 1982 (15,633 facilities). The 1982 NCRF surveyed registries of facilities constructed within each state which were compiled from (a) state, regional, and county mental retardation program licensing agencies, state offices reimbursing contracted services, and other state or regional offices maintaining listings of licensed or contracted providers, (b) the 1982 *Directory of Public Residential Facilities for the Mentally Retarded* maintained by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, and (c) facilities surveyed by the Center for Residential and Community Services (CRCS) in its earlier 1977 NCRF survey. As noted above the 1982 NCRF counted nearly 244,000 persons with mental retardation in facilities licensed or contracted to serve persons with mental retardation and related conditions. In addition to number of residents, facility level data were gathered on resident characteristics, facility administration and costs, resident movement and in other areas. The methods and findings of the 1982 NCRF, with some comparative findings from the 1977 NCRF, can be found in the survey's summary report (Lakin, Hill, & Bruininks, 1985).

In 1986, the National Center on Health Statistics (NCHS) conducted a first-time survey called the Inventory of Long-Term Care Places. The content and approach used for the ILTCP was largely based on the National Master Facility Inventory, a mail census of nursing and related care facilities, periodically updated by NCHS. However, the scope of facilities in the ILTCP was expanded to include facilities for persons with mental retardation. The ILTCP was designed specifically as the sampling frame for the Institutional Population Component of the 1987 National Medical Expenditure Survey, and will be discussed in considerable detail in that regard later in this report

### **Sample Surveys**

In addition to the census surveys since 1980 there have been two sample based surveys including residents with mental retardation in different types of institutions have been conducted over the years. These include the National Nursing Home Survey and the National Medical Expenditure Survey.

The National Center for Health Statistics has conducted sample surveys of residents of long-term care facilities since 1963. The earlier surveys were known as the Resident Places Surveys (1963, 1964, and 1969). Later, NCHS initiated the National Nursing Home Survey as an ongoing data collection system. It is based on a facility sample, and a resident sample drawn from sampled facilities. The sample frame has been the National Master Facility Inventory. The National Nursing Home Survey has been conducted by NCHS three times, in 1973-74, 1977, and 1985. Each of the surveys has collected data that describe the facilities and data on a sample of the current residents, which includes typically 125-200 sample members indicated to have mental retardation or a related condition. In 1977 and again in 1985, the survey included an additional component that described people discharged from the nursing home during the previous calendar year, providing useful information on the outcomes of nursing home stays. Outcomes of discharge included whether sample members returned to a community residence (i.e., their own homes), or were transferred to another health care facility or hospital.

Although conducted prior to 1980, there are two sample based surveys deserving attention as precursors to the National Medical Expenditure Survey. In 1976, the Bureau of the Census conducted the Survey of Institutionalized Persons for the Department of Health and Human Services on persons in all kinds of institutions, including those for persons with mental retardation. The survey included detailed sample data on persons living in a wide range of long-term care facilities, including nursing homes, facilities for children, facilities for persons with physical handicaps, facilities for persons with mental illness, facilities for persons with mental retardation, and persons in chronic disease hospitals. Data were collected about the institution, sampled residents, and the resident's family. The survey findings have not been widely used, in part because of a significant flaw that was discovered in the sample frame, resulting in a substantial underrepresentation of persons in mental retardation and mental health facilities. However, this survey still represents the most recent data on persons in certain kinds of specialized long-term care facilities.

In 1978-1979 the University of Minnesota conducted a sample survey of 236 public and private residential facilities for persons with mental retardation and approximately 2,000 individual residents. The 1977 NORF served as the sample frame for that study. Detailed data were gathered on resident demographic, functional, medical and behavioral characteristics, programs and services received, daily experiences and relationships, and on facility characteristics and costs. The study also gathered extensive data on residents in movement among facilities and gathered useful data on persons providing care in the residential settings surveyed (Hauber, Bruininks, Wieck, Sigford, & Hill, 1981).

The Institutional Population Component of the National Medical Expenditure Survey, the subject of this report, was conducted in 1987 by the National Center for Health Services Research (now the U.S. Agency for Health Care Policy and Research). It represents the most recent effort to gather national data on populations of residential settings for persons with mental retardation and related conditions. The methodology and instruments used in this survey are described in some detail elsewhere (Edwards and Edwards, 1989). Generally, the National Medical Expenditure Survey was intended to respond to the need for national

information on access to medical care, health insurance, health and disability-related losses of productive activity, and utilization of and expenditures for a range of medical care including physician visits, other medical provider visits, hospital stays, and drugs, equipment and supplies. It focused on gathering nationally representative statistics on health care utilization and expenditures in the United States. It was the third such effort since 1977. The two early studies, the National Medical Care Expenditure Survey (NMCES) and the National Medical Care Utilization and Expenditure Survey (NMCUES), were conducted in 1977 and 1980, respectively. The 1987 NMES survey was similar to these earlier studies in its gathering of a wide range of health care utilization and expenditures data on members of approximately 14,000 households in the United States. However, because of the rapidly growing expenditures for care in institutional and related settings under Medicaid and other public and private programs, an "Institutional Population Component," with large samples of nursing homes and mental retardation facilities and their residents were also drawn (3,347 and 3,618 current residents, respectively). In all during 1987 data were collected on samples of persons living in about 14,000 private households, 800 nursing and personal care homes, and 700 facilities for persons with mental retardation. Notably absent from the NMES Institutional Population Component were mental health facilities and people living in them.

In general, then, there have been a range of studies including persons with mental retardation and related conditions in institutional settings in recent years. A major strength of the National Medical Expenditure Survey was specifically its effort to provide comparable data on persons with different types of conditions in different types of settings. As more of these data become available, the benefits of the integrated inclusion of persons in a range of long-term care settings will undoubtedly prove useful. On the other hand, as discussed in the following pages, the effort to broaden the coverage of settings and individuals as represented in NMES also dramatically increases the challenges of doing so well.

This report contains only the data obtained in NMES on mental retardation facilities and their residents. Its purpose is to provide a summary of the findings obtained on mental retardation facilities and their residents in the first phase of the NMES (the only data available at this writing). As part of this analysis, the report also examines certain aspects of the NMES design and sample frame which effect the national estimates obtained.

## **Methodology**

The success of any effort to obtain an unbiased, representative, sample of facilities and their residents is dependent on comprehensive identification of all (or as close to all as possible) facilities in the universe of facilities of the type being studied. Because most sample studies attempt to make population estimates by weighting sample members by the reciprocal of their proportion of the universe, the extent to which the sample frame includes all facilities of the type being studied (and thereby includes their residents), determines the success of efforts to estimate the population. In addition, the extent to which exclusions or omissions from the sample frame tends to be disproportionately distributed across different subpopulations within the universe affects not only the population estimates, but also the

proportional representation of certain groups which may be of interest. Of course, problems in acquiring the universe of all facilities from which an unbiased sample can be drawn are found to some extent in all sample surveys of long-term care settings and their residents to some extent. Given the range of different types of facilities (from foster care to large institutions), the different levels and types of agencies licensing and monitoring the different settings (from local to state), and the variability across states and among agencies within the same states, it is practically impossible to develop a sample frame containing absolutely all long-term care settings of interest. The challenge is to establish one which contains as much of the universe of programs of interest as is possible.

### **The NMES Sample Frame**

The sample frame of Mental Retardation Facilities in the Institutional Population Component of the National Medical Expenditure Survey was the Inventory of Long-Term Care Places. Like all sample frames it has its limitations. The most notable of these were: (1) it did not include the full universe of facilities, and (2) it disproportionately excluded certain types of facilities and, thereby, certain subpopulations of residents. The limitations evident in the sample frame of the Institutional Population Component probably can be expected to have had two important effects on the outcomes of the study. First, because the sample frame appears not to have included large numbers of facilities and residents who were in the universe for which information was desired, the samples selected are not weighted so as to provide precise estimates of the population of all mental retardation facilities. Specifically, because sample members (facilities and residents) are weighted by the proportion of the sample frame they represent, the fact that the true universe of interest (all long-term care facilities) is considerably larger than the sample frame results in an underestimation of total mental retardation facilities and residents. Second, because the sample frame underidentifies specific types of facilities within the universe of interest, NMES contains underrepresentation of specific subpopulations of facilities and residents within its sample. It is relatively easy to identify the subpopulations of facilities and residents that are underrepresented. Unfortunately, it is difficult to say with confidence how adjustments might be made to correct for these limitations, although simple considerations of how this might be done are provided in Part 3 of this report. Underrepresentation of certain types of facilities has a direct effect on estimations of the size and characteristics of their resident populations, but there are indirect population estimation problems that may be just as significant. For example, children tend to reside in higher proportions in small facilities than do adults. Because small facilities are considerably less comprehensively included in the sample frame than were large facilities, children make up a disproportionately small part of the sample and of the estimated population than is the case in reality. In addition, the overall depiction of the residential status of children in mental retardation facilities is probably skewed toward larger, institutional settings.

### **Definition and Identification of Facilities**

The 1986 Inventory of Long-Term Care Places, which was conducted specifically to provide a sample frame for NMES. Specific findings on mental retardation facilities from the

ILTCP have been published by the National Center on Health Statistics (Sirrocco, 1989). For the purposes of establishing the sample frame for NMES, the ILTCP served to identify facilities primarily serving persons with mental retardation, verify eligibility as a “mental retardation facility”, and to provide statistics on population and administrative characteristics of facilities on which the sample stratification and eventual weighting could be based.

For the purposes of this study the universe of all mental retardation facilities of interest was defined as: state licensed, contracted or operated living quarters which provided 24-hour, 7-days-a-week responsibility for room, board and supervision of mentally retarded persons. This definition excluded households providing services to relatives and residential service and support programs in which staff did not provide continuous supervision.

**Construction of the registry.** Prior to the actual “inventory” portion of the ILTCP, a list of facilities potentially meeting the definition of a mental retardation facility was constructed using the 1982 National Census of Residential Facilities for persons with mental retardation of the Center for Residential and Community Services, University of Minnesota. To that registry of 15,633 facilities were added facilities reported by states and “relevant associations” in the latter half of 1985, which did not appear on the CRCS registry. No known documentation is available on the number of facilities added to the original NCRF-based registry as part of this process, or how those facilities were distributed by type, size or state.

**Surveying the registry (the ILTCP).** The Inventory of Long-Term Care Places was a simultaneous survey of mental retardation facilities identified as described above and nursing and related care homes identified in a similar manner using the 1982 National Master Facility Inventory as the base list of nursing and related care facilities. To complete the ILTCP, the Bureau of the Census surveyed 56,728 total facilities using a 4-page questionnaire that was identical for all facilities, irrespective of the registry from which they were originally identified. Of these 56,728 facilities, statistics reported by staff of the National Center for Health Services Research (NCHSR) (Potter, Cohen & Mueller, 1987) indicate that 5,808 could not be surveyed because of insufficient address or telephone information, inability to locate or contact individual names, and the eventual dropping of individual nonrespondents. There were 174 direct refusals to participate. Another 5,500 places on the registry were not operating as residential facilities at the time of the survey, or residential services were not being provided at the specific address, for example, in the case of home offices for groups of residential facilities.

The ILTCP survey outcomes were used by NCHSR to evaluate all 56,728 facilities in the registry for their status as a mental retardation facility. This was done according to a set of hierarchical decision rules. The process eliminated from the sample frame facilities that were nursing or related care homes, duplicate addresses or otherwise out-of-scope. For example, these rules led to exclusion of 233 facilities not providing full-time supervision and another 434 for having no residents with mental retardation at the time of the Inventory.

Originally, the Institutional Population Component's sample frame was intended to include all types and sizes of mental retardation facility meeting the operational definition.

However, during the sampling process, it became clear that the sample frame included substantially fewer small facilities than were identified in the 1982 National Census of Residential Facilities for persons with mental retardation of the University of Minnesota. As noted in a NCHSR staff paper on the NMES sample frame development (Potter, Cohen & Mueller, 1987).

A final comparison of the 1986 ILTCP MR universe to the 1982 NCRF universe (Hauber, et al. 1984) suggested undercoverage of one and two bed MR facilities by the ILTCP. A likely explanation is that the very small MR facilities are more likely to close or move than large facilities (Hauber, et al., 1984). This jeopardized completeness of the frame, so one and two bed MR's were deleted at the end of the eligibility determination process (p. 9)

A separate analyses of the ILTCP by NCHS (Sirrocco, 1987) noted procedural differences in the surveys that may have accentuated the difference noted above:

In creating the mailing list for the MR portion of the ILTCP, NCHS started with a file produced in 1982 by the University of Minnesota's Center for Residential and Community Services (CRCS). The 15,000 MR facilities on the file were matched against current state and local directories obtained by NCHS. Due to time constraints imposed on the ILTCP, NCHS was unable to contact all local sources identified by CRCS in its study. It is believed that most of all places missed would be small MR facilities (fewer than 16 beds).

***Comparison of NCHSR and NCHS identification of mental retardation facilities.***

Discrepancies existed between NCHSR and NCHS determinations of what constituted a mental retardation facility in the ILTCP. This must be expected when confronted with thousands of "generic" residential facilities operating across the country with more than one categorical disability evident among the people living there (i.e., people who are mentally retarded, elderly/disabled, and/or mentally ill). To exemplify the difficulty in determining facility types, NCHSR determined that the ILTCP included 17,265 mental retardation facilities, 1914 of which had 1 or 2 residents. NCHS on the other hand, determined that there were 14,639 mental retardation facilities, 1350 of which had 1 or 2 residents. NCHSR determined that the ILTCP contained 12,914 mental retardation facilities with 3-15 residents, NCHS identified 11,353. In short, even once physically located, the determination that a place is a mental retardation facility as opposed to some other type of residential setting is often not easily nor reliably accomplished.

***Comparison of sample frame with state reports.*** The Center for Residential and Community Services at the University of Minnesota conducts annual surveys of state mental retardation/developmental disabilities agencies to obtain aggregated statistics on persons with mental retardation in residential facilities that are licensed, contracted or operated by states to provide residential services for persons with mental retardation and related conditions. The reports gathered for June 30, 1986 provide a useful point of comparison for the ILTCP sample frame, which was gathered in the first half of 1986. According to states on

June 30, 1986, they had a total of 251,908 persons with mental retardation residing in 29,285 separate mental retardation “facilities”. They identified 2,080 facilities of 16 or more residents (147,719 total residents with mental retardation) and 27,205 facilities of 15 or fewer residents (104,189 total residents with mental retardation). The NCHS analysis of the ILTCP indicated 1,936 facilities of 16 or more residents and 12,703 facilities with 15 or fewer residents.

**Comparison of multiple sources.** Table 1 briefly summarizes comparative statistics related to the completeness of the ILTCP coverage and NMES population estimates. Available analyses of the ILTCP (Sirrocco, 1987, 1989) have included only total residents (both with and without mental retardation). However, assuming that the proportion of mentally retarded to total residents in the ILTCP is similar to that found in the 1982 NCRF (which, as noted earlier, was the basis for the ILTCP registry of mental retardation facilities), the 14,639 facilities in the NCHS analyses with a total resident population of 250,472 would be estimated to house 217,164 individuals with mental retardation (the 1982 NCRF found 86.7% of the residents of mental retardation facilities were persons with mental retardation). Again, using data from the 1982 NCRF, the estimated number of mentally retarded residents in small facilities (15 or fewer residents) in the ILTCP would be 89.3% of the total 73,493 residents, or 65,627 residents with mental retardation. Using the same procedure, residents with mental retardation in large facilities would be estimated to be 85.8% of total residents of mental retardation facilities or 151,881 individuals. Table 1 contains four comparative statistics: (1) the findings of the 1982 NCRF; (2) the estimates of total number of residents of mental retardation facilities from the NCHS analysis of the 1986 ILTCP, with estimates of the proportion of total residents with mental retardation based on the findings of the 1982 NCRF; (3) state reports of total residents with mental retardation as of June 30, 1986; and (4) the population estimates from the 1987 National Medical Expenditure Survey.

**TABLE 1. Comparison of the Population Estimates of the National Medical Expenditure Survey with Related Studies**

Study	MR Facilities			Residents w/MR			Total Residents		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
1982 NCRF	13,862	1,771	15,633	63,703	179,966	243,669	71,338	209,704	281,042
1986 ILTCP*	12,703	1,936	14,639	65,627 (e)	151,881 (e)	217,508 (e)	73,493	176,979	250,472
1986 State Reports	27,205	2,080	29,285	104,189	147,719	251,906	116,782 (e)	172,211 (e)	288,993 (e)
1987 NMES Est.*	11,054	2,276	13,330	64,936	153,697	218,633	69,481	170,137	239,619

\*Note: Since issuance of the data tape used in these analyses, the staff of the Agency for Health Care Policy and Research (formerly the National Center for Health Services Research) has undertaken extensive efforts to identify and correct for facility duplication in the Inventory of Long-Term Care Places (ILTCP). A relative large amount of duplication was noted in the ILTCP, which served as the sample frame for NMES. Because these duplications increased the probability of certain facilities and thereby certain residents being sampled, sample weights were recomputed to adjust for the increased probability of selection due to duplication of facilities in the sample frame. The resulting adjustments have reduced the estimated number of mental retardation facilities by 7.8% and the total number of people living in those facilities by about 12%. Presumably the resulting reduction in estimates of residents with mental retardation and related conditions is somewhat less. These reweightings increase further the disparity between estimates obtained in the NMES and those obtained from other sources. Statistics followed by an “(e)” are estimates based on the proportion of residents with mental retardation to total residents obtained in the 1982 NCRF.

Statistics presented in Table 1 show the National Medical Expenditure Survey to provide population estimates of persons with mental retardation in mental retardation facilities of 16 or more residents which appear close to what would be expected given other sources of information. But, with respect to smaller facilities substantial differences exist. The total number of persons estimated to be in small facilities in the NMES is very similar to the number obtained in the 1982 NCRF. But much is known to have changed in residential services between 1982 and 1987. In their annual reports to the Center for Residential and Community Services, states indicated that their small residential facilities housed 104,189 people with mental retardation on June 30, 1986. This represents a large increase from 1982, but one which is corroborated by the same state statistics showing a large decrease in residents of facilities with 16 or more residents. The statistics obtained in the state reports, the ILTCP, and even the NMES population estimates, all indicate large mental retardation facility populations of around 150,000 or about 30,000 less than 1982. Most of this population decrease took place because of people being moved to small facilities. Underidentification of persons in small facilities was further reflected in the differences between ILTCP and NMES estimates of the total population of persons with mental retardation in residential care (about 218,000) and the total number identified in the 1982 NCRF (244,000) and the 1986 state reports (252,000). Even including the 1 and 2 person facilities identified in the ILTCP, the estimated population of people with mental retardation and related conditions in mental retardation facilities in the NMES would have been only about 220,000-221,000 persons. This is about 25,000-30,000 fewer than the other available comparative statistics. (See the note at the foot of Table 1 for additional comments on this disparity.)

In summary then, it is clear that the ILTCP and as a result, the National Medical Expenditure Survey substantially undercounted persons with mental retardation. It also seems clear that this undercount is confined to facilities of 15 or fewer residents. The magnitude of the undercount appears to be over 30,000 small facility residents (including facilities with 1 or 2 residents), or in the neighborhood of one-third of all small facility residents.

Analyzing whether there are any particular subpopulations of small facilities and residents that were systematically undercounted in NMES could be accomplished by state-by-state analyses using state reports and state-by-state breakdowns of facilities on the ILTCP. It would also be possible to hypothesize about effects of the general undercounting and the associated elimination of all facilities with 2 or fewer residents from the sample frame. For example, specialized (mental retardation/developmental disabilities) foster care settings are underrepresented because they are more likely to have 1 or 2 residents. Therefore, children and youth are probably underrepresented because they are somewhat more likely to live in specialized foster homes. Still despite its limitations in the representation of small facility populations, it is important to stress that the NMES provides much useful data on both small and large facilities and their residents. In Part 2 of this report the first available sets of these data are presented and briefly discussed. In Part 3 some consideration is given to the possibility of ways to use the NMES data to adjust the

population estimates to make them more reflective of the known universe of mental retardation facilities and people living in them.

## **PART 2: FINDINGS OF THE NATIONAL MEDICAL EXPENDITURE SURVEY**

Part 2 of this report examines the data obtained from the Facility and Baseline (Resident) questionnaires on the “mental retardation facilities” in the Institutional Population Component of the 1987 National Medical Expenditure Survey. These were the only data yet available at the time of these analyses. Subsequent data will permit examination of service utilization, costs of services, and other aspects of living in long-term care settings. In the following presentations of data, descriptive statistics such as percentages and averages are generally used in place of population estimates. This is done because of the evidence of substantial underestimation of the population of small facility residents. In addition to tables presenting the results of the analyses and discussion of the findings, this chapter also includes brief comments on the nature and quality of the instrumentation related to the concepts being studied.

### **Organization of Analyses and Tables**

In these analyses of the “mental retardation facilities” in the Institutional Population Component of NMES, three basic facility groupings are used. They are: (1) facility operation (private for profit, private nonprofit and government operated, with size breakdowns of 15 and fewer residents/16 or more residents within each type of operation); (2) ICF-MR certification (ICF-MR certified or not ICF-MR certified, with size breakdowns of 15 or fewer residents/16 or more residents within each group); and (3) facility size (breakdowns of facilities by “set up bed” categories of 3-6, 7-15, 16-75, 76-299, 300-799, and 800+). Number of set up beds was used as the indicator of size because specific facility resident population data were not made available in the NMES public use data tape. Again it is noted that all “facilities” of under 3 residents were excluded from the NMES survey.

### **Descriptive Estimates by Facility Groupings**

Table 2, Table 3 and Table 4 present breakdowns of NMES population estimates for number of mental retardation facilities, set up beds, current residents and residents with mental retardation and related conditions for the 3 facility groupings (type of operation, ICF-MR status, facility size). Discrepancies between these population estimates and what might be expected based on other data sources were noted in Part 1. Again, most significantly, the estimated 64,936 persons with mental retardation and related conditions in facilities with 15 or fewer residents was substantially less than the 104,189 persons with mental retardation that states reported in 1986 (the year in which the NMES sample frame was established). Only a small part of the discrepancy (10% or less) can be attributed to the decision to eliminate all the facilities of 1 and 2 residents that were in the sample

frame. Discrepancies between NMES estimates and state reports of the number of large facilities, private and government operated, and the number of people living in them, is much less, and within the normal expectations of differences due to sampling. Indeed, had the total resident variable been available for categorizing facilities by size rather than requiring the use of “set up” beds, the difference between the state reports of 147,719 persons with mental retardation and related conditions in facilities of 16 or more residents and the NMES estimate of 153,619 persons with mental retardation and related conditions in facilities of 16 or more residents, would have been even smaller.

**Grouping 1: Facility operation.** Table 2 presents summary statistics on facilities by type of operation. The primary limitations in the NMES population estimates are among the private facilities and most specifically the small private facilities. The estimated number of such facilities and residents is considerably below the numbers known and reported by state mental retardation/developmental disabilities agencies. NMES estimates of government operated facilities and large private facilities are generally similar to what states reported for mid-1986, about the time the sample frame was developed (Lakin, Hill, White, & Wright, 1987).

**Grouping 2: ICF-MR certification status.** Table 3 presents summary statistics on facility groupings by ICF-MR/non-ICF-MR status. The NMES estimates of populations of both large and small ICF-MR facilities are quite similar to the statistics reported by states at the time the NMES sample frame was being developed (Lakin et al., 1987). States reported that on June 30, 1986 they had 20,890 residents with mental retardation and related conditions in small ICFs-MR. The NMES estimated 21,077. For the same date, states reported 122,925 persons with mental retardation and related conditions in large ICFs-MR. The NMES estimated 118,084. As noted before, non-certified facilities appear substantially underestimated in NMES when compared to state reports, with almost all of the discrepancy being in the smaller (15 or fewer resident) facilities.

**Grouping 3: Facility size.** Table 4 presents summary statistics on facility groupings by size (“set up beds”). Again, the problems with the NMES sample and population estimation appear generally limited to the smaller facilities. Whereas NMES estimated that in early 1987 11,054 facilities of 15 or fewer residents had 64,935 people with mental retardation living in them, states reported on June 30, 1986 that they had 27,205 facilities with 104,189 people living in them (Lakin et al., 1987). The population estimates from NMES indicate that the average size of facilities with 15 or fewer “set up beds” was 5.9 residents. Using state reported data of June 30, 1986, the average size of facilities with 15 or fewer *residents* (including facilities serving one or two residents, which were excluded from NMES) was about 2.4 residents.

TABLE 2. Facility Grouping 1, Facility Operation												
	Private For Profit			Private NonProfit			Public			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
N of facility	4,701	1,019	5,720	5,214	747	5,962	1,138	510	1,648	11,054	2,276	13,330
Set up beds	30,018	47,196	77,214	35,502	37,349	72,851	8,348	104,999	113,347	73,867	189,544	263,411
Current res	25,629	44,676	70,304	36,050	31,557	67,607	7,803	93,904	101,707	69,481	170,137	239,619
MR/RC res	21,712	31,919	53,632	35,590	30,237	65,827	7,633	91,541	99,174	64,936	153,697	218,633

**Notes.** Numbers of facilities are weighted estimates based on the facility questionnaire data. Facility size is based upon the number of set up beds in reporting unit. The total facility may be larger than the reporting unit although this is presumably seldom the case. The number of residents is commonly less than the number of set up beds. National estimates of current residents from the Baseline (resident) Questionnaire and "set up beds" from the Facility Questionnaire Indicate the former to be 91.0% of the latter. Number of current residents include residents who do not have mental retardation (MR) or a related condition (RC). Number of MR/RC residents (mental retardation and related conditions) we weighted estimates from the resident baseline questionnaire. All references to MR mean MR/RC. Government operated facilities include those operated by city, county, or state. One 600 bed facility with missing data for "owner" was assumed to be government operated. Because data are weighted and rounded to nearest whole number, some totals may not equal 100%.

TABLE 3. Facility Grouping 2, ICF-MR Certification Status									
	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
N of facility	3,330	904	4,235	7,724	1,372	9,095	11,054	2,276	13,330
Set up beds	24,083	130,580	154,663	49,784	58,964	108,748	73,867	189,544	263,411
Current res	21,420	123,089	144,509	48,062	47,048	95,109	69,481	170,137	239,619
MR/RC res	21,077	118,084	139,161	43,859	35,613	79,472	64,936	153,697	218,633

**Notes.** Numbers of facilities are weighted estimates based on the facility questionnaire data. Facility size is based upon the number of set up beds in reporting unit. The total facility may be larger than the reporting unit although this is presumably seldom the case. The number of residents is commonly less than the number of set up beds. National estimates of current residents from the Baseline (resident) Questionnaire and "set up beds" from the Facility Questionnaire Indicate the former to be 91.0% of the latter. Number of current residents include residents who do not have mental retardation (MR) or a related condition (RC). Number of MR/RC residents (mental retardation and related conditions) we weighted estimates from the resident baseline questionnaire. All references to MR mean MR/RC. There are no 800+ bed non-ICFs-MR in the sample. Based on analysis of their size and operation, facilities with missing data for "ICF-MR" were assumed to be not certified. Because data are weighted and rounded to nearest whole number, some totals may not equal 100%.

TABLE 4. Facility Grouping 3, Facility Size							
	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
N of facility	7,098	3,956	1,720	417	116	23	13,330
Set up beds	33,900	39,967	55,794	53,712	55,213	24,825	263,411
Current res	30,118	39,363	50,711	48,435	54,555	16,436	239,619
MR/RC res	28,241	36,694	40,580	44,194	52,487	16,436	218,633

Notes. Numbers of facilities are weighted estimates based on the facility questionnaire data. Facility size is based upon the number of set up beds in reporting unit. The total facility may be larger than the reporting unit although this is presumably seldom the case. The number of residents is commonly less than the number of set up beds. National estimates of current residents from the Baseline (resident) Questionnaire and “set up beds” from the Facility Questionnaire indicate the former to be 91.0% of the latter. Number of current residents include residents who do not have mental retardation (MR) or a related condition (RC). Number of MR/RC residents (mental retardation and related conditions) we weighted estimates from the resident baseline questionnaire. All references to MR mean MR/RC.

## Facility Administrative Data

Table 5 and Table 6 present basic administrative statistics for ICF-MR and noncertified facilities by type of operation and facility size. The statistics presented on facility capacity, current residents and certified capacity have the limitations discussed above.

### Proportion of Capacity Occupied

Data from the 1987 National Medical Expenditure Survey indicate occupancy of mental retardation facilities to be 90.2% of the maintained capacity of facilities. ICF-MR certified facilities had an occupancy of 92.0%. The noncertified facilities were 87.5% occupied. Small ICFs-MR reported a 8-9.0% occupancy rate; large ICFs-MR an 94% occupancy. The lowest occupancy rates were among the large prime non-ICF-MR facilities (78.7%). Facilities of 800 or more residents had by far the lowest proportions of their reported maintained capacity currently occupied (66.2%). In fact, although facilities of 800 or more residents had only 9.4% of the total estimated maintained capacity, they had 35.3% of the unoccupied maintained capacity.

### Proportion of Residents with Mental Retardation and Related Conditions

Based on NMES data, 91.2% of the residents of mental retardation facilities were persons with mental retardation and related conditions. Prime for profit facilities were most likely to have residents who were reported not to have mental retardation and related

conditions (23.6% of residents). Among non-ICF-MR, private for profit facilities, an estimated 32.3% of residents did not have mental retardation or related conditions.

### **Medicaid Certified Capacity**

According to the National Medical Expenditure Survey, mental retardation facilities nationwide had a total of 156,736 “beds” certified for Medicaid participation. The Medicaid capacity within mental retardation facilities was overwhelmingly concentrated in the ICF-MR program (98.7%). The estimates of Skilled Nursing Facility (SNF) and Intermediate Care Facility (ICF) capacities (584 and 1,489 total “beds” respectively) were based on so few sampled facilities that they cannot be considered reliable estimates of SNF and ICF certification of units in mental retardation facilities.

The Medicaid participation in mental retardation facilities was indicated to be highly concentrated in large facilities. About 84% of total (ICF-MR, ICF and SNF) Medicaid certified capacity was estimated to be in large facilities, as was 84% of ICF-MR certified capacity alone. Generally speaking, the smaller the facility grouping the less likely it was to have its residential capacity certified for Medicaid participation. For example, facilities with 800 or more residents had 100% of their capacity Medicaid certified; those with 300-799 residents were 96.6% certified; those with 76-299 residents were 66.9% certified; and facilities with 16-75 residents were 31.3% certified. The undercounting of small (less than 16 residents) facilities is confined almost exclusively to small, noncertified facilities which greatly affects estimated proportion of small facility capacity certified. While the NMES estimated that 32.6% of small facility capacity was ICF-MR certified, and that 32.5% of small facility residents with mental retardation and related conditions were in ICF-MR units, state reports of small facilities and small facilities with ICF-MR certifications for 1987 indicated 19.8% to be ICF-MR certified (Lakin et al., 1989).

### **Direct Care Personnel**

Substantial differences were found among facilities in their ratios of direct care personnel to their total current “set up beds.” Generally, NMES indicated that there were now more people providing direct care nationally than are receiving it (1.06:1). But given 168 hours in a week and the prevailing 40 hour work week, this translated to an average resident to direct care staff ratio of about 4 to 1 at any one time. Ratios of staff to residents were highest in the (overlapping) categories of ICF-MR certified facilities (1.33:1), government operated facilities (1.48:1) and large facilities (1.18:1). The lowest ratios were among non-ICFs-MR (.66:1), private for profit facilities (.61:1), and small facilities (.72:1). Small for profit facilities had the lowest staff to resident ratios for both certified and non-certified facilities (.60 and .44 staff member's per resident, respectively). One factor in these lower ratios was the fact that in many of the smaller proprietary facilities the owner/operators lived in the “facility” and were providing care and supervision for considerably more hours than was indicated by their treatment as a single full-time direct care position. Another important factor in the lower ratios was, as will be described later,

that the residents of these facilities generally appeared to have less extensive needs for care and supervision than did residents of other types of facilities.

### **Per Diem Costs**

A major limitation of the NMES facility data was that costs were coded into 5 broad cost categories from continuous cost statistics that were originally gathered. The categories created for the NMES data and the weighted proportion of residents within the facilities of each range were: (a) \$30 or less per day (23.5%), (b) \$31-\$55 (14.8%), (c) \$56-\$80 (15.6%), (d) \$81-\$105 (14.2%), and (e) \$106 or more per day (31.8%). Based on other surveys (Hill et al., 1989; White, Lakin, Hill, Wright, & Bruininks, 1988), facility costs generally range from \$15 to well over \$300 per day, so that the extreme data reduction in the NMES data files drastically decreased the usefulness of the facility cost statistics.

ICF-MR certified facilities, regardless of operator or size, were much less likely to be found in the lower cost ranges (e.g., \$55 per day or less) than non-certified facilities. Among private for profit facilities, 83% of residents in non-certified facilities were in places with a daily cost of \$55 or less as compared with 51% of residents of ICFs-MR. Among nonprofit facilities, 64% of residents in non-certified facilities and 35% of those in ICFs-MR were in places with a cost of \$55 or less. Among government operated facilities, 21% of non-certified facility residents were in places costing \$55 or less per day, as compared with an estimated 1% of persons in public ICFs-MR. Conversely, an estimated 65% of public and private ICF-MR facility residents were in places that cost \$81 or more per day as compared with 18% of persons in non-certified facilities.

**TABLE 5. Basic Administrative Data by ICF-MR Certification Status and Facility Operation**

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public					
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total
<b>ICF-MR Certified</b>												
Total maintained capacity	7,188	20,779	27,967	13,394	11,796	25,189	3,501	100,375	103,876	24,083	130,580	157,033
Total current residents	6,264	18,409	24,673	12,153	12,703	24,856	3,003	89,607	92,610	21,420	123,089	144,509
Total MR/RC residents	6,128	18,228	24,356	11,946	12,302	24,248	3,004	87,554	90,556	21,077	118,084	139,161
Total ICF-MR beds	7,188	18,409	25,598	13,393	11,796	25,189	3,501	100,375	103,876	24,083	123,089	154,663
Direct care per bed	0.60	1.02	0.91	1.06	0.91	0.99	10.70	1.54	1.53	0.92	1.41	1.33
Per diems by range												
\$1-\$30	29.0%	13.5	17.7	11.3	23.4	17.1	7.7	0.0	0.2	16.5	4.0	5.9
31-55	21.3	51.5	43.3	15.1	20.8	17.9	0.0	0.8	0.8	15.1	10.1	10.8
56-80	38.7	27.6	30.6	37.5	20.1	29.1	20.1	12.5	12.7	35.6	15.4	18.4
81-105	0.0	7.4	5.4	21.2	15.7	18.5	35.5	23.2	23.6	16.3	20.2	19.6
106+	11.1	0.0	3.0	14.9	20.1	17.4	36.7	63.5	62.8	16.5	50.3	45.4
<b>Not ICF-MR Certified</b>												
Total maintained capacity	22,830	28,786	51,616	23,897	25,554	47,661	4,847	4,624	9,461	49,784	58,964	108,748
Total current residents	19,365	23,896	43,261	23,897	18,854	42,751	4,800	4,297	9,098	48,062	47,048	95,109
Total MR/RC residents	15,584	13,691	29,275	23,644	17,935	41,579	4,631	3,987	8,618	43,859	35,613	79,472
Total SNF/ICF beds	427	745	1,173	0	0	0	649	250	899	1,076	995	2,072
Direct care	0.44	0.46	0.45	0.76	0.88	0.83	0.90	0.97	0.94	0.63	0.69	0.66
Per diems by range												
\$1-\$30	76.4%	67.5	71.1	42.6	28.3	34.2	22.9	13.3	17.6	55.7	45.0	49.5
31-55	5.5	16.7	12.2	30.2	30.3	30.2	30.8	0.0	13.9	19.4	21.8	20.8
56-80	5.4	8.7	7.4	13.9	19.5	17.2	0.4	11.3	6.4	8.9	14.0	11.9
81-105	5.0	3.6	4.2	4.0	7.8	6.3	19.7	14.3	16.7	5.8	6.4	6.2
106+	7.8	3.5	5.2	9.3	14.1	12.1	26.1	61.1	45.3	10.1	12.8	11.7
<b>All Facilities</b>												
Total maintained capacity	30,018	47,196	77,214	35,502	37,349	72,851	8,348	104,999	113,347	73,867	189,544	265,781
Total current residents	25,629	44,676	70,304	36,050	31,557	67,607	7,803	93,904	101,707	69,481	170,137	239,619
Total MR/RC residents	21,712	31,919	53,632	35,590	30,237	65,827	7,633	91,541	99,174	64,936	153,697	218,633
Total Medicaid beds	7,615	19,154	26,769	13,394	11,796	25,189	4,150	100,624	104,775	25,160	131,575	156,735

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public			15-res.	16+ res.	Total
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total			
Total ICF-MR beds	7,188	18,409	25,598	13,394	11,796	25,189	3,501	100,375	103,876	24,083	130,580	154,663
Direct care	0.48	0.69	0.61	0.87	0.89	0.88	0.97	1.51	1.48	0.72	1.18	1.06
Per diems by range												
\$1-\$30	63.3	45.3	51.7	30.7	26.9	28.6	16.3	0.6	1.5	42.2	17.1	23.5
31-55	9.9	31.0	23.5	24.4	27.6	26.2	17.5	0.8	1.8	17.9	13.8	14.8
56-80	14.6	16.5	15.8	22.9	19.7	21.1	8.9	12.4	12.2	18.1	14.9	15.7
81-105	3.6	5.2	4.6	10.6	10.1	10.3	26.5	22.8	23.0	9.4	15.8	14.2
106+	8.7	2.1	4.4	11.4	15.8	13.8	30.7	63.4	61.4	12.3	38.4	31.8

**Notes.** Total maintained capacity is number of set up beds in reporting unit, estimated from weighted data on facility questionnaire. Total current residents and residents with MR/RC we weighted estimates from resident baseline questionnaire. Most facilities with Medicaid certification (78.4%) we indicated to be 100% certified. For other facilities with Medicaid certification, total ICF, ICF-MR, and SNF beds we estimated to be the number of set up beds multiplied by the midpoint of multiple categories (e.g., 0-10% = 5%) of the recoded variables "percent of beds certified." Facilities with missing bad certification data but which are ICF-MR certified are assumed to be 100% ICF-MR. Per diems by range are the estimated percentage of residents in each facility category living in facilities in each per diem range. Facility size weights are "set up beds." Direct care personnel estimates are expressed as number of FTE direct care staff (licensed nurses, nurses aids/orderlies, recreating/activity staff, and "all other care staff") per set up bad. "Part time" assumed to equal 50% FTE. Data are weighted to represent correct proportions of set up beds (approximately equal to the number of residents). Row and column totals may not be equal because of differences in missing data across cells.

**TABLE 6. Basic Administrative Data by ICF-MR Certification Status and Facility Size**

	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>ICF-MR Certified</b>							
Total maintained capacity	10,233	13,850	17,503	34,926	53,326	24,825	154,663
Total current residents	8,871	12,549	19,190	34,747	52,717	16,436	144,509
Total MR/RC residents	8,528	12,549	17,979	32,553	51,117	16,436	139,161
Total ICF-MR beds	10,233	13,850	17,503	34,926	53,326	24,825	154,663
Direct care	0.88	0.95	1.32	1.34	1.56	1.21	1.33
Per diems by range							
\$1-\$30	36.3%	0.0	11.1	8.7	0.0	0.0	5.9
31-55	7.3	21.6	20.7	24.8	0.0	0.0	10.8
56-80	21.3	47.5	17.6	14.1	14.1	18.5	18.4
81-105	21.8	11.7	14.0	8.4	30.3	22.5	19.6
106+	13.2	19.2	36.6	44.0	55.7	59.0	45.4
<b>Not ICF-MR Certified</b>							
Total maintained capacity	23,667	26,117	38,291	18,787	1,887	0	108,748
Total current residents	21,247	26,814	31,521	13,689	1,838	0	95,109
Total MR/RC residents	19,713	24,146	22,602	11,642	1,370	0	79,472
Total SNF/ICF beds	427	649	0	995	0	0	2,072

	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
Direct care	0.68	0.58	0.62	0.84	0.52	0.00	0.66
Per diems by range							
\$1-\$30	50.3%	59.7	47.5	38.3	67.0	0.0	49.5
31-55	10.1	26.1	25.8	12.6	33.0	0.0	20.8
56-80	12.5	6.4	7.9	27.7	0.0	0.0	11.9
81-105	8.7	3.7	4.3	11.3	0.0	0.0	6.2
106+	18.4	4.1	14.5	10.1	0.0	0.0	11.7
<b>All Facilities</b>							
Total maintained capacity	33,900	39,967	55,794	53,712	55,213	24,825	263,411
Total current residents	30,118	39,363	50,711	48,435	54,555	16,436	239,619
Total MR/RC residents	28,241	36,694	40,580	44,194	52,487	16,436	218,633
Total Medicaid beds	10,661	14,499	17,503	35,921	53,326	24,825	156,735
Total ICF-MR beds	10,233	13,850	17,503	34,926	53,326	24,825	154,663
Direct care	0.74	0.71	0.83	1.54	1.54	1.21	1.06
Per diems by range							
\$1-\$30	45.2%	39.9	36.5	18.6	1.9	0.0	23.5
31-55	9.1	24.6	24.2	20.7	0.9	0.0	14.8
56-80	15.7	20.0	10.8	18.6	13.7	18.5	15.7
81-105	13.5	6.4	7.2	9.3	29.4	22.5	14.2
106+	16.5	9.1	21.2	32.8	54.1	59.0	13.8
<p><u>Notes.</u> Total maintained capacity is number of set up beds in reporting unit, estimated from weighted data on facility questionnaire. Total current residents and residents with MR/RC we weighted estimates from resident baseline questionnaire. Most facilities with Medicaid certification (78.4%) we indicated to be 100% certified. For other facilities with Medicaid certification, total ICF, ICF-MR, and SNF beds we estimated to be the number of set up beds multiplied by the midpoint of multiple categories (e.g., 0-10% = 5%) of the recoded variables "percent of beds certified." Facilities with missing bad certification data but which are ICF-MR certified are assumed to be 100% ICF-MR. Per diems by range are the estimated percentage of residents in each facility category living in facilities in each per diem range. Facility size weights are "set up beds." Direct care personnel estimates are expressed as number of FTE direct care staff (licensed nurses, nurses aids/orderlies, recreating/activity staff, and "all other care staff") per set up bad. "Part time" assumed to equal 50% FTE. Data are weighted to represent correct proportions of <u>set up beds</u> (approximately equal to the number of residents). Row and column totals may not be equal because of differences in missing data across cells.</p>							

## Resident Movement

Table 7 and Table 8 present basic resident movement statistics for calendar year 1986 for ICF-MR and noncertified facilities by type of operation and size. Movement is expressed as a percentage of the "current residents." Movement data were based on Facility Questionnaire responses, but included only facilities open for all of 1986. This had the effect of underestimating admissions to small facilities which generally have very high occupancy and which as a class tend to increase their total resident population by the

creation of new facilities rather than increasing number of people in existing facilities. Again, underrepresentation of small facilities may have affected the reported rates.

### **Admission/Discharge Rates**

In general, the facilities that were most active in admissions and discharges during 1986 were the smallest facilities (3-6 residents) and the private for profit facilities. The 3-6 person facilities had admissions in 1986 equal to 18.9% of their residential population. They had discharges equal to 14.2% of their residential population. Private for profit facilities reported admissions equal to 19.1% of total residents and discharges equal to 14.6% of their residents. Movement was considerably higher in facilities without ICF-MR certification than in the ICFs-MR (16.2% vs. 9.0% for admissions and 14.0% vs. 9.9% for discharges).

### **Deaths**

The estimated national death rate in residential facilities serving persons with mental retardation was 1.4% of the resident population. This compares with a rate of 1.2% obtained in the 1982 NCRF (Lakin, Hill, & Bruininks, 1985). One factor in the difference between the two estimates was the underrepresentation of small facilities in which the death rate was on average approximately half that of the larger institutions (.9% vs. 1.6%). But there may also have been a small actual increase. Compared with the 1982 NCRF, the estimated death rates for both small and large facilities was larger on small facilities, .7% in the 1982 NCRF and .9% in the 1987 NMES; in large facilities, 1.5% in the 1982 NCRF and 1.6% in the 1987 NMES although either difference could have been due to sampling error). But increases in death rates might be expected in both types of facilities as both types house increasingly aging populations and populations which are more severely impaired.

### **Net Population Change**

Public institutions continued to experience depopulation as a result of considerably higher discharges and deaths (9.7% and 1.4%, respectively) than admissions (6.7%). The net reduction of 4.4% during 1986 was part of the general depopulation of public institutions from 1982 to 1987 (from 117,160 average daily residents to 94,696, or an annual average decrease of 4.2%) (Lakin et al., 1989). Not population losses were greatest among institutions with 300 or more residents (5.4%).

**TABLE 7. Basic Resident Movement by ICF-MR Certification and Facility Operation**

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public			15-res.	16+ res.	Total
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total			
<b>ICF-MR Certified</b>												
Total current residents	6,264	20,779	27,043	12,153	12,703	24,856	3,003	89,607	92,610	21,420	123,089	144,509
Average 1986 admission rate	19.0	14.5	15.8	11.5	9.8	10.7	10.8	6.6	6.8	13.6	8.0	9.0
Average 1986 live discharge rate	14.3	12.1	12.8	8.7	8.0	8.4	3.9	9.7	9.5	9.8	9.9	9.9
Average 1986 death rate	0.8	1.7	1.5	0.8	1.7	1.2	0.0	1.4	1.4	0.7	1.5	1.4
Rate of wait listing	11.0	11.0	11.0	27.9	23.7	25.8	15.1	3.4	3.6	21.0	6.2	7.9
<b>Not ICF-MR Certified</b>												
Total current residents	19,365	23,896	43,261	23,897	18,854	42,751	4,800	4,297	9,098	48,062	47,048	95,109
Average 1986 admission rate	21.5	20.4	20.9	12.8	10.3	11.6	15.9	8.9	12.5	17.1	15.4	16.2
Average 1986 live discharge rate	15.1	16.0	15.6	12.8	12.3	12.5	15.6	10.0	12.9	14.1	14.0	14.0
Average 1986 death rate	1.5	2.4	2.0	0.5	1.4	0.9	0.8	1.4	1.1	1.0	1.9	1.5
Rate of wait listing	3.8	5.6	4.9	12.2	37.3	26.2	13.0	0.8	4.8	7.3	15.1	11.8
<b>All Facilities</b>												
Total current residents	25,629	44,676	70,304	36,050	31,556	67,607	7,803	93,904	101,707	69,481	170,137	239,619
Average 1986 admission rate	20.9	18.1	19.1	12.3	10.1	11.2	13.9	6.7	7.3	15.9	10.2	11.9
Average 1986 live discharge rate	14.9	14.4	14.6	11.1	10.8	11.0	10.9	9.7	9.8	12.6	11.1	11.5
Average 1986 death rate	1.3	2.1	1.8	0.6	1.5	1.0	0.5	1.4	1.3	0.9	1.6	1.4
Rate of wait listing	5.1	7.9	6.9	18.5	32.4	26.0	13.8	3.3	3.7	11.3	8.9	9.4

Notes. Movement data are expressed as percent of set up beds. Table includes only facilities that were open all of 1986. It excludes a small number of facilities whose number of admissions or number of releases exceeded bed capacity. Certain facilities serve as diagnostic, placement and/or crisis centers. They receive and discharge large number of residents each year. These were excluded in order to reflect the movement status of persons in typical residential settings.

**TABLE 8. Basic Resident Movement by ICF-MR Certification and Facility Size**

	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>ICF-MR Certified</b>							
Total current residents	8,871	12,549	19,190	34,747	52,717	16,436	144,509
1986 admission rate	17.7	10.6	16.1	10.4	6.8	2.5	9.0
1986 live discharge rate	11.3	8.6	10.8	10.4	11.7	4.6	9.9
1986 death rate	0.8	0.6	2.7	1.1	1.3	1.7	1.4
Rate of wait listing	7.8	33.4	24.3	7.2	2.5	1.2	7.9
<b>Not ICF-MR Certified</b>							
Total current residents	21,247	26,814	31,521	13,689	1,838	0	95,109
1986 admission rate	19.4	14.9	14.8	16.5	18.4	0.0	16.2
1986 live discharge rate	15.6	12.7	12.9	16.7	14.3	0.0	14.0
1986 death rate	1.1	0.9	2.0	1.7	1.0	0.0	1.5
Rate of wait listing	6.5	8.2	18.1	8.7	3.1	0.0	11.8
<b>All Facilities</b>							
Total current residents	30,118	39,363	50,711	48,435	54,555	16,436	239,619
1986 admission rate	18.9	13.4	15.2	12.2	7.2	2.5	11.9
1986 live discharge rate	14.2	11.3	12.3	12.2	11.8	4.6	11.5
1986 death rate	1.0	0.8	2.2	1.3	1.3	1.7	1.4
Rate of wait listing	6.9	16.0	19.9	7.6	2.5	1.2	9.4
<p><u>Notes.</u> Movement data are expressed as percent of set up beds. Table includes only facilities that were open all of 1986. It excludes a small number of facilities whose number of admissions or number of releases exceeded bed capacity. Certain facilities serve as diagnostic, placement and/or crisis centers. These receive and discharge large number of residents each year. They were excluded in order to reflect the movement status of persons in typical residential settings.</p>							

### Waiting Lists

Facilities were asked to report the number of people they had wait listed for placement in their facilities. Considerable caution must be exercised in considering these statistics. Individuals may have been on more than one facility list, overestimating the unduplicated count of people waiting. Second, use of waking lists (even among facilities with no people currently listed) were reported by only 60.5% of the small facilities. This reflects a tendency for decisions about access to some facilities (and the lists of people waiting) to be maintained outside the facility. Such tendencies underestimate the total

number of people waiting. It cannot be determined how these factors affected the estimate of 22,500 people being on waiting lists. Facility maintained waiting lists were relatively long in facilities of 7-15 residents and 16-75 residents, particularly among those with ICF-MR certification (on the average 33.4% and 24.3% of their current residents, respectively). Facilities of 16 or more residents reported waiting lists of about 15,150 people. Perhaps most striking in the waiting list statistics was the size of the waiting lists for the “intermediate” size institutions of 16 to 75 residents (almost 10,100 persons).

## **Resident Characteristics**

The following tables present data on a range of diagnostic, medical and functional skills of residents of mental retardation facilities grouped by type of operation, ICF-MR certification status, and facility size. The estimates are from the Baseline Questionnaire.

### **Level of Retardation/Type of Related Conditions**

Table 9, Table 10 and Table 11 present the levels of retardation or types of related conditions for mental retardation facility residents reported to have mental retardation, epilepsy, cerebral palsy, autism, and/or spina bifida. Under “mentally retarded” are presented the estimated distribution of residents by level of retardation for individuals indicated to have mental retardation. Under “Related Conditions Only” are the estimates of prevalence of certain conditions among sample members who were indicated to have epilepsy, cerebral palsy, autism or spina bifida, but not mental retardation.

**Persons with mental retardation.** The NMES estimates indicated that 99% of the residents of mental retardation facilities who had mental retardation or related conditions, had mental retardation. The same proportion was found in both large and small facilities. It is notable, however, that of the persons indicated to have “mental retardation,” 4% were classified as “borderline mentally retarded” or not technically within the range of measured intelligence (i.e., 10) currently recognized as indicating mental retardation.

People with profound retardation made up an estimated 37% of the residents in mental retardation facilities. They were concentrated in large facilities (46% of residents in those facilities), particularly in large government operated ones (60% of residents), and in ICF-MR certified facilities (49% of residents). About 18% of the residents of the 3 to 6 resident facilities were persons with profound retardation.

The overall prevalence of mild/borderline, moderate and severe mental retardation among residents of mental retardation facilities was quite similar (20.9%, 21.0% and 20.5% of all residents, respectively). The prevalence of severe mental retardation was relatively consistent across the various types of facilities examined (from a low of 17% of residents in government facilities with 800 residents to 33% in government facilities with 15 or fewer residents). The distribution of persons with mild/moderate mental retardation (including borderline) varied much more across facility categories. For example, while

62% of persons in facilities of 15 and fewer residents had mild/moderate mental retardation, only 18% of persons in facilities of 300 or more residents were classified as mild or moderately mentally retarded. Mild/moderate mental retardation had a much higher prevalence within non-certified residential facilities (64% of residents) than within ICFs-MR (30%).

**TABLE 9. Residents with Mental Retardation and Related Conditions in Mental Retardation Facilities by Level of Mental Retardation or Related Conditions and Facility Operation**

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public					
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total
<b>Mentally Retarded</b>												
Mild/Borderline	29.3	27.2	28.1	32.7	31.9	32.4	24.2	8.7	9.9	30.6	16.9	20.9
Moderate	31.4	24.5	27.3	34.4	25.1	30.2	17.4	11.4	11.9	31.4	16.7	21.0
Severe	25.6	18.0	21.0	20.2	17.5	19.0	32.7	21.1	21.1	23.5	19.2	20.5
Profound	11.1	28.6	21.6	12.5	23.6	17.6	25.5	56.9	56.9	13.6	46.3	36.7
Total	97.4	98.3	98.0	99.8	98.1	99.2	99.8	99.8	99.8	99.1	99.1	99.1
<b>Related Conditions Only</b>												
Epilepsy only	1.7	1.5	1.6	0.2	0.8	0.5	0.0	0.2	0.2	0.7	0.6	0.6
Cerebral palsy only	0.7	0.0	0.3	0.0	1.0	0.5	0.0	0.0	0.0	0.2	0.2	0.2
Autism only	0.2	0.0	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.0	0.0
Spina bifida only	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Multiple related conditions	0.0	0.2	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.1
Total	2.6	1.7	2.0	0.2	1.8	1.0	0.0	0.2	0.2	1.0	0.9	0.9
<small>Notes. Statistics presented are proportion of total estimated population in each facility category indicated to have either mental retardation or a related condition by level of mental retardation or, if not indicated to have mental retardation, by a related condition. Columns may not add to 100% because of rounding. Statistics on residents with "related conditions only" are based only on 33 of the total 3,616 sample members.</small>												

People with conditions related to mental retardation (i.e., epilepsy, cerebral palsy, autism and/or spina bifida), but who were not also reported to be mentally retarded appeared to be rare among mental retardation facilities (an estimated less than 1%). Because individuals with related conditions only were represented by just 33 persons in the entire sample, estimates of their characteristics are subject to considerable error. However, among the sample epilepsy was the most commonly reported condition of persons who did not have mental retardation, but made up only an estimated 0.6% of all residents with mental retardation and related conditions. Although residents were rarely reported to have related conditions only, the following section shows these conditions very commonly accompanied mental retardation among the residents of mental retardation facilities. However, it is important to note that many persons with related conditions reside in facilities primarily serving populations with conditions other than mental retardation. A

description of these individuals will be included in subsequent analyses of data on nursing and related care facility residents.

<b>TABLE 10. Residents with Mental Retardation and Related Conditions in Mental Retardation Facilities by Level of Mental Retardation or Related Conditions and Certification Status</b>									
	<b>ICF-MR Certification Status</b>						<b>All Facilities</b>		
	<b>ICF-MR Certified</b>			<b>Not Certified</b>			<b>15-res.</b>	<b>16+ res.</b>	<b>Total</b>
	<b>15-res.</b>	<b>16+ res.</b>	<b>Total</b>	<b>15-res.</b>	<b>16+ res.</b>	<b>Total</b>			
<b>Mentally Retarded</b>									
Mild/Borderline	29.8	11.8	14.6	30.9	35.0	32.7	30.6	16.9	20.9
Moderate	27.7	13.4	15.6	33.2	28.3	31.0	31.4	16.7	21.0
Severe	25.4	19.7	20.5	22.6	17.5	20.3	23.5	19.2	20.5
Profound	16.5	54.5	48.8	12.1	17.4	14.5	13.6	46.3	36.7
Total	99.4	99.4	99.5	98.8	98.2	98.5	99.1	99.1	99.1
<b>Related Conditions Only</b>									
Epilepsy only	0.2	0.4	0.4	9.0	1.2	1.1	0.7	0.6	0.6
Cerebral palsy only	0.3	0.2	0.2	0.2	0.3	0.2	0.2	0.2	0.2
Autism only	0.0	0.0	0.0	0.1	0.0	0.0	0.1	0.0	0.0
Spina bifida only	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Multiple related conditions	0.0	0.0	0.0	0.0	0.2	0.1	0.0	0.0	0.0
Total	0.5	0.6	0.6	1.2	1.7	1.4	1.0	0.8	0.8
<p><b>Notes.</b> Statistics presented are proportion of total estimated population in each facility category indicated to have either mental retardation or a related condition by level of mental retardation or, if not indicated to have mental retardation, by a related condition. Columns may not add to 100% because of rounding. Statistics on residents with "related conditions only" are based only on 33 of the total 3,616 sample members.</p>									

**TABLE 11. Residents with Mental Retardation and Related Conditions in Mental Retardation Facilities by Level of Mental Retardation or Related Conditions and Facility Operation**

	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>Mentally Retarded</b>							
Mild/Borderline	27.2	33.4	31.7	18.1	8.1	7.3	20.9
Moderate	29.8	32.5	26.3	18.3	9.5	13.0	21.0
Severe	23.9	23.2	17.5	21.8	19.1	16.9	20.5
Profound	17.8	10.4	22.7	40.9	63.0	62.9	36.7
Total	98.7	99.3	98.2	99.1	99.7	100.1	99.1
<b>Related Conditions Only</b>							
Epilepsy only	0.7	0.7	1.3	0.6	0.3	0.0	0.6
Cerebral palsy only	0.5	0.0	0.3	0.4	0.0	0.0	0.2
Autism only	0.1	0.0	0.0	0.0	0.0	0.0	0.0
Spina bifida only	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Multiple related conditions	0.0	0.0	0.2	0.0	0.0	0.0	0.0
Total	1.3	0.7	1.8	1.0	0.3	0.0	0.9
<p><b>Notes.</b> Statistics presented are proportion of total estimated population in each facility category indicated to have either mental retardation or a related condition by level of mental retardation or, if not indicated to have mental retardation, by a related condition. Columns may not add to 100% because of rounding. Statistics on residents with “related conditions only” are based only on 33 of the total 3,616 sample members.</p>							

### **Related Conditions by Level of Retardation**

Table 12, Table 13 and Table 14 present estimates of the prevalence of conditions related to mental retardation among residents with different levels of mental retardation. Specific conditions included are epilepsy, cerebral palsy, autism, spina bifida and deafness or blindness. Table 12 presents estimates for facilities by type of operation; Table 13 by ICF-MR certification and Table 14 by facility size.

**Epilepsy.** Approximately 29.6% of persons with mental retardation residing in mental retardation facilities were estimated to have epilepsy. The presence of epilepsy was clearly associated with the level of mental retardation. About 15% of persons with mild mental retardation were reported to have epilepsy as compared with 43% of persons with profound mental retardation. Persons with epilepsy were most likely to be in facilities of 16 or more residents (34% of residents had epilepsy), large government operated facilities (40% with epilepsy) and ICF-MR certified facilities (34% with epilepsy). Controlling for level of retardation, with the exception of persons with mild or borderline

mental retardation, persons with epilepsy were more likely to be residing in larger facilities than persons whose medical records did not indicate a seizure disorder.

**Cerebral palsy.** An estimated 12% of persons with mental retardation and related conditions in mental retardation facilities were reported to have cerebral palsy. As with epilepsy, there was a clear association between cerebral palsy and level of mental retardation of residents. Cerebral palsy was noted in the medical records of an estimated 5.5% of the individuals with mild or borderline mental retardation, 6.4% of those with moderate mental retardation, 9.2% of those with severe mental retardation, and 19.5% of those with profound mental retardation. Related to this general association with level of retardation, persons with cerebral palsy were more likely to be found in facilities of 16 or more residents than in smaller facilities (13% versus 8%). The prevalence of cerebral palsy was estimated to be slightly higher in large private facilities than in large public facilities (15% vs. 12%). An estimated 13.5% of ICF-MR residents and 8.5% of residents of non-ICF-MR facilities had cerebral palsy.

**Autism.** An estimated 3.5% of residents of mental retardation facilities had autism noted in their medical records. The prevalence of reported autism was highest among persons with severe mental retardation (5.6%). Estimated rates of autism among persons with moderate and profound mental retardation were 3.3% and 3.6%, respectively. An estimated 1.4% of individuals with mild or borderline retardation were reported to be autistic. Only 5.4% of the persons reported not to be mentally retarded were reported to have autism, but this estimate was based on only 2 of 3,618 sample members. The estimated prevalence of autism was similar in large (16+ residents) and small facilities (3.7% and 3.0% respectively). The highest prevalence of autism was reported in larger nonprofit facilities (8.9%). ICF-MR certified facilities had a considerably lower reported prevalence of autism among its populations (2.5%) than did the noncertified facilities (5.4%).

**Spina bifida.** Spina bifida was estimated to be rare among the mental retardation facility populations. It was consistently reported to be below 1% for individuals of all levels of mental retardation and in all sizes and types of facilities.

**Blind or deaf.** An estimated 7% of persons in mental retardation facilities were blind and/or deaf. Prevalence of these conditions was associated with level of mental retardation; from 2.3% of persons with mild or borderline mental retardation to 13.8% of persons with profound retardation. Persons who were blind or deaf were more likely to reside in facilities of 16 or more residents (8.7% compared with 3.7% in smaller facilities). The prevalence of deafness or blindness among facility populations was closely associated with facility size (from 3.0% in facilities of 6 or fewer residents, and 4.2% in facilities of 7-15 residents, to 10.2% in facilities 300-799 residents, and 12.8% in facilities of 800 or more residents). About twice the proportion of persons in ICFs-MR were deaf or blind (8.8%) than in facilities that were not ICF-MR certified (4.3%).

**TABLE 12. Number and Types of Related Disabilities Among Residents of Mental Retardation Facilities by Facility Operation**

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public			15-res.	16+ res.	Total
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total			
<b>Mentally Retarded</b>												
Borderline/Mild												
Epilepsy	19.1	15.3	16.9	15.6	12.1	14.0	4.8	17.5	15.1	15.6	14.8	15.2
Cerebral Palsy	3.1	3.7	3.5	6.8	9.1	7.8	7.4	2.6	3.5	5.7	5.3	5.5
Autism	0.6	2.5	1.7	0.9	3.2	1.9	0.0	0.0	0.0	0.7	2.0	1.4
Spina Bifida	0.0	1.4	0.8	0.4	0.7	0.5	0.0	0.0	0.0	0.3	0.7	0.5
Blind or Deaf	1.4	2.7	2.2	4.5	0.7	2.8	0.0	2.1	1.7	3.1	1.8	2.3
Moderate												
Epilepsy	19.9	15.9	17.7	16.0	21.5	18.1	17.1	33.4	31.5	17.3	24.7	21.5
Cerebral Palsy	4.8	9.5	7.4	6.7	9.2	7.6	3.1	3.2	3.2	5.9	6.8	6.4
Autism	2.0	2.2	2.1	2.0	8.5	4.5	0.0	3.2	2.9	1.9	4.5	3.3
Spina Bifida	0.9	0.9	0.9	0.5	0.9	0.7	0.0	1.1	0.9	0.6	1.0	0.8
Blind or Deaf	1.4	5.5	3.6	2.3	4.4	3.1	7.6	4.6	4.9	2.4	4.8	3.7
Severe												
Epilepsy	20.3	19.2	19.7	16.5	17.6	17.0	31.9	36.1	35.6	20.4	29.6	26.5
Cerebral Palsy	10.7	12.6	11.7	3.8	10.8	6.7	28.7	6.7	9.3	10.4	8.6	9.2
Autism	9.4	1.3	5.2	6.0	14.2	9.5	2.2	3.7	3.5	6.5	5.1	5.6
Spina Bifida	0.0	0.0	0.0	0.0	1.4	0.6	0.0	0.5	0.4	0.0	0.6	0.4
Blind or Deaf	4.5	1.8	3.1	3.8	8.6	5.8	3.3	4.4	4.2	4.0	4.6	4.4
Profound												
Epilepsy	36.5	43.4	42.1	26.1	36.1	32.3	25.1	46.3	45.5	28.6	44.9	43.2
Cerebral Palsy	17.2	33.2	29.9	10.7	30.2	22.6	17.4	16.8	15.8	13.9	20.2	19.5
Autism	6.2	3.3	3.9	5.6	13.7	10.7	0.0	2.2	2.2	4.5	3.5	3.6
Spina Bifida	0.0	0.0	0.0	1.8	0.0	0.7	0.0	0.6	0.6	0.9	0.5	0.5
Blind or Deaf	8.2	9.0	8.8	6.0	17.1	12.9	12.3	15.1	15.0	8.0	14.5	13.8
<b>Related Conditions Only</b>												
Epilepsy	66.3	100.0	82.8	100.0	43.5	49.9	0.0	100.0	100.0	70.1	75.9	74.1
Cerebral Palsy	26.7	0.0	13.7	0.0	56.5	50.1	0.0	0.0	0.0	23.7	24.1	24.0
Autism	7.0	12.3	9.6	0.0	0.0	0.0	0.0	0.0	0.0	6.2	5.0	5.4
Spina Bifida	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Blind or Deaf	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
<b>Total Residents with MR/RC</b>												
Epilepsy	22.8	25.6	24.5	17.4	21.7	19.3	21.0	40.4	38.9	19.6	33.8	29.6
Cerebral Palsy	7.8	15.1	12.2	6.6	15.2	10.6	16.2	12.0	12.3	8.2	13.2	11.7
Autism	4.1	2.6	3.2	2.9	8.9	5.6	0.7	2.5	2.3	3.0	3.7	3.5
Spina Bifida	0.3	0.6	0.5	0.5	0.7	0.6	0.0	0.6	0.5	0.4	0.6	0.5
Blind or Deaf	2.9	5.0	4.2	3.8	6.9	5.2	5.5	10.5	10.2	3.7	8.7	7.2

**Notes.** Blindness is defined as inability, with use of corrective lenses, to recognize (because of visual acuity) familiar people at a distance of 2 or 3 feet. Deafness is defined as inability, with a hearing aid, to hear things said to him or her. Data on "related conditions only" are percent of residents reported not to have mental retardation within each of five types of related condition, who have the additional condition listed. Within groups, columns do not always total 100% because some residents with related conditions only had more than one listed. "Total residents with MR/RC" includes percentage of all residents with and without MR who have the listed conditions. Only 33 sample members (out of 3,618 total) were indicated to have "related conditions only."

**TABLE 13. Number and Types of Related Disabilities Among Residents of Mental Retardation Facilities by Certification Status**

	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified			15- res.	16+ res.	Total
	15- res.	16+ res.	Total	15- res.	16+ res.	Total			
<b>Mentally Retarded</b>									
Borderline/Mild									
Epilepsy	18.9	15.7	16.7	14.0	13.8	13.9	15.6	14.8	15.2
Cerebral Palsy	5.2	7.9	7.1	6.0	2.4	4.2	5.7	5.3	5.5
Autism	0.0	1.1	0.8	1.1	3.0	2.0	0.7	2.0	1.4
Spina Bifida	0.0	1.3	0.9	0.4	0.0	0.2	0.3	0.7	0.5
Blind or Deaf	2.1	2.4	2.3	3.5	1.0	2.3	3.1	1.8	2.3
Moderate									
Epilepsy	22.7	26.7	25.6	15.1	21.5	17.7	17.3	24.7	21.5
Cerebral Palsy	5.7	7.3	6.9	5.9	5.9	5.9	5.9	6.8	6.4
Autism	3.1	2.8	2.9	1.4	7.2	3.8	1.9	4.5	3.3
Spina Bifida	1.1	1.5	1.4	0.4	0.0	0.2	0.6	1.0	0.8
Blind or Deaf	2.3	6.1	5.1	2.4	2.7	2.5	2.4	4.8	3.7
Severe									
Epilepsy	18.5	32.5	29.9	21.5	18.1	20.2	20.4	29.6	26.5
Cerebral Palsy	10.9	8.8	9.2	10.1	7.6	9.2	10.4	8.6	9.2
Autism	4.6	3.6	3.7	7.6	11.3	9.1	6.5	5.1	5.6
Spina Bifida	0.0	0.4	0.3	0.0	1.3	0.5	0.0	0.6	0.5
Blind or Deaf	3.0	4.3	4.1	4.5	5.8	5.0	4.0	4.6	4.4
Profound									
Epilepsy	27.6	44.6	43.3	29.2	48.4	39.6	28.6	44.9	43.2
Cerebral Palsy	5.3	19.7	19.0	19.7	25.1	22.5	13.9	20.2	19.5
Autism	2.1	2.5	2.4	6.1	15.0	10.9	4.5	3.5	3.6
Spina Bifida	0.0	0.5	0.5	1.5	0.0	0.7	0.9	0.3	0.5
Blind or Deaf	10.9	14.2	14.0	6.1	17.8	12.4	8.0	14.5	13.8
<b>Related Conditions Only</b>									
Epilepsy	33.0	72.1	66.8	78.1	80.3	79.3	70.1	75.9	74.1
Cerebral Palsy	67.0	27.9	33.2	14.4	19.7	17.3	23.7	24.1	24.0
Autism	0.0	0.0	0.0	7.5	10.6	9.2	6.2	5.0	5.4
Spina Bifida	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Blind or Deaf	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
<b>Total Residents with MR/RC</b>									
Epilepsy	21.4	36.6	34.3	18.7	23.9	21.0	19.6	33.8	29.6
Cerebral Palsy	7.1	14.6	13.5	8.7	8.5	8.6	8.2	13.2	11.7
Autism	2.3	2.6	2.5	3.3	7.9	5.4	3.0	3.7	3.5
Spina Bifida	0.4	0.7	0.7	0.4	0.2	0.3	0.4	0.6	0.5
Blind or Deaf	3.9	9.7	8.8	3.6	5.2	4.3	3.7	8.7	7.2

	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified			15- res.	16+ res.	Total
	15- res.	16+ res.	Total	15- res.	16+ res.	Total			
<p><b>Notes:</b> Blindness is defined as inability, with use of corrective lenses, to recognize (because of visual acuity) familiar people at a distance of 2 or 3 feet. Deafness is defined as inability, with a hearing aid, to hear things said to him or her. Data on "related conditions only" are percent of residents reported not to have mental retardation within each of five types of related condition, who have the additional condition listed. Within groups, columns do not always total 100% because some residents with related conditions only had more than one listed. "Total residents with MR/RC" includes percentage of all residents with and without MR who have the listed conditions. Only 33 sample members (out of 3,618 total) were indicated to have "related conditions only."</p>									

TABLE 14. Number and Types of Related Disabilities Among Residents of Mental Retardation Facilities by Facility Size							
	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>Mentally Retarded</b>							
Borderline/Mild							
Epilepsy	13.3	17.1	13.2	16.1	18.2	10.6	15.2
Cerebral Palsy	5.0	6.2	6.5	4.9	4.4	0.0	5.5
Autism	1.0	0.5	3.6	0.9	0.0	0.0	1.4
Spina Bifida	0.0	0.4	0.9	0.8	0.0	0.0	0.5
Blind or Deaf	3.1	3.1	1.0	2.7	0.0	10.6	2.3
Moderate							
Epilepsy	24.3	12.5	21.1	22.3	31.3	36.3	21.5
Cerebral Palsy	3.1	7.8	6.3	10.9	2.7	3.3	6.4
Autism	3.3	0.9	4.7	4.6	3.9	4.1	3.3
Spina Bifida	0.7	0.5	0.7	0.8	2.2	0.0	0.8
Blind or Deaf	0.7	3.5	4.7	4.0	2.8	12.6	3.7
Severe							
Epilepsy	22.3	19.0	21.3	26.7	37.5	31.3	26.5
Cerebral Palsy	12.3	9.0	5.5	15.0	5.6	4.9	9.2
Autism	8.9	4.7	10.3	3.5	3.6	3.9	5.6
Spina Bifida	0.0	0.0	1.1	0.0	0.9	0.0	0.4
Blind or Deaf	1.7	5.7	6.7	3.7	4.9	1.9	4.4
Profound							
Epilepsy	34.0	21.7	43.4	43.0	46.4	44.7	43.2
Cerebral Palsy	13.5	14.4	36.6	21.9	16.8	14.0	19.5
Autism	4.3	4.7	10.7	2.7	1.9	4.0	3.6
Spina Bifida	1.6	0.0	0.0	0.0	0.6	1.2	0.5
Blind or Deaf	8.8	7.0	16.4	13.1	14.3	16.1	13.8
<b>Related Conditions Only</b>							
Epilepsy	51.2	100.0	82.8	57.3	100.0	0.0	74.1
Cerebral Palsy	38.7	0.0	17.2	42.7	0.0	0.0	24.0
Autism	10.1	0.0	9.2	0.0	0.0	0.0	5.4
Spina Bifida	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Blind or Deaf	0.0	0.0	0.0	0.0	0.0	0.0	0.0
<b>Total Residents with MR/RC</b>							
Epilepsy	22.8	17.1	24.8	31.0	41.1	38.9	29.6

	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
Cerebral Palsy	8.1	8.2	13.4	15.5	12.3	10.1	11.7
Autism	4.3	2.1	6.8	2.8	2.3	3.7	3.5
Spina Bifida	0.5	0.3	0.7	0.3	0.8	0.8	0.5
Blind or Deaf	3.0	4.2	6.4	7.4	10.2	12.8	7.2

Notes. Blindness is defined as inability, with use of corrective lenses, to recognize (because of visual acuity) familiar people at a distance of 2 or 3 feet. Deafness is defined as inability, with a hearing aid, to hear things said to him or her. Data on "related conditions only" are percent of residents reported not to have mental retardation within each of five types of related condition, who have the additional condition listed. Within groups, columns do not always total 100% because some residents with related conditions only had more than one listed. "Total residents with MR/RC" includes percentage of all residents with and without MR who have the listed conditions. Only 33 sample members (out of 3,618 total) were indicated to have "related conditions only."

### Age Distribution of Residents

Table 15, Table 16 and Table 17 present estimates of the age distribution of persons with mental retardation and related conditions in mental retardation facilities. Age distribution estimates are provided for all residents and separately for those with mild/moderate levels of mental retardation, those with severe/profound mental retardation, and those who only had related conditions. It should be noted that the exclusion of facilities with 1 or 2 residents and the general underrepresentation of other small "family care" facilities has likely caused some degree of underestimation of the proportion of children and youth in mental retardation facilities. This was due to the somewhat greater proportion of children and youth in small family care settings than in other facilities (51% greater than all other facilities in the 1982 NCRF, Lakin, Hill, & Bruininks, 1985). Based on statistics from the 1982 NCRF it would appear likely the proportion of children and youth in all residential facilities in 1987, including those of 1 and 2 residents, was greater than the 15.5% estimated in the NMES. Adjustments for the undercounted smaller facilities and the eliminated 1 and 2 person placements, based on NCRF would suggest that children and youth (21 years and younger) made up 18.5% to 19.5% of the population of mental retardation facilities. While not insignificant, this magnitude of undercounting is relatively minor for the sake of this discussion. It is assumed that the estimates of the ages of the residents of mental retardation facilities obtained from NMES were generally accurate for facilities of 16 or more residents.

Like earlier studies, the NMES showed clearly the overwhelmingly adult population in mental retardation facilities. It estimated that only 15.5% of persons with mental retardation and related conditions in mental retardation facilities were persons 21 years and younger. Even the adjusted estimate of 18.5% to 19.5% was considerably less than the 24.8% found in the 1982 NCRF and 37.4% found in the 1977 NCRF (Lakin, Hill, & Bruininks, 1985). Data suggested continued decreases in the proportion and actual number of both children (0-14 years) and adolescents (15-21 years) in mental retardation facilities. The 1982 NCRF indicated that 9.1% of residents were children (0-14 years) as compared with 4.6% in the 1987 NMES. The 1982 NCRF facilities indicated 15.5% of residents were adolescents (15-21 years), as compared with 10.8% in the 1987 NMES.

At the other end of the life span populations of mental retardation facilities are aging. According to NMES 5.5% of mental retardation facility residents were 65 years or older. This compares with 5.0% 63 years or older in the 1982 NCRF and 4.1% in the 1977 NCRF (Lakin, Hill, & Bruininks, 1985). The middle-age bracket also continued to increase, with 19.9% of residents 40-62 years in 1977, 23.3% of residents 40-62 years in 1982 and 27.5% 40-64 years in 1987.

Age distributions within large and small facilities were quite similar. Private for profit facilities had the highest proportion of older residents, private nonprofit facilities had the highest proportion of younger residents. Only 13.6% of the population of large government facilities was made up of persons 21 years or younger. This compared with 22.0% in the 1982 NCRF and 35.8% of the 1977 NCRF. ICF-MR facilities had smaller proportions of children and youth than non-ICF-MR facilities (13.7% and 18.4% respectively). They also had a higher proportion of persons 65 years or older (5.8% vs. 4.8%).

Resident age distributions were associated with level of retardation. Resident populations indicated to have mild or moderate levels of retardation contained lower proportions of children and youth than did the populations indicated to be severely or profoundly mentally retarded (12.2% vs. 17.9%). This was not only generally true, but was true within all facility sizes and types. Conversely, higher proportions of older mental retardation facility residents were indicated to be mildly or moderately mentally retarded than were indicated to be severely or profoundly mentally retarded. Of all mildly/moderately retarded residents 9.4% were persons 55-64 years, and 6.7% were persons 65 years or older. Of all severely/profoundly retarded residents, only 6.3% were persons 55-64 years, and 4.3% were 65 years or older. These differences reflect the lower life expectancy of persons with profound mental retardation. But the generally increasing life expectancy of persons with mental retardation, the current efforts to avoid their unnecessary placements in nursing homes, and the presence in mental retardation facilities of about 20,000 persons in the 55-64 year age range will produce a great increase in the elderly population of mental retardation facilities by the end of this century.

The concentration of the residential population in early adulthood (22 to 39 years) was notable. While only 30.8% of the U.S. population was between 22 and 39 years at the time of this study, an estimated 51.6% of the population of mental retardation facilities in 1987 was in young adulthood. This bulge is the result of placement factors such as the relatively low placements of children and youth in residential settings, and relatively high numbers of placements of older people with mental retardation and related conditions in nursing homes, an estimated 13,000 according to the 1985 National Nursing Home Survey.

**TABLE 15. Age Distribution of Residents of Mental Retardation Facilities by Level of Retardation and Facility Operation**

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public					
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total
<b>Mentally Retarded</b>												
Borderline/Mild/Moderate												
0-14 years	6.6	2.3	4.2	0.1	5.1	2.2	4.0	3.9	3.9	2.6	3.8	3.3
15-21 years	6.8	4.2	5.3	9.1	18.3	13.0	8.2	5.7	6.1	8.2	9.4	8.9
22-39 years	40.1	43.2	41.8	58.9	48.2	54.4	43.1	51.0	49.8	51.4	47.6	49.2
40-54 years	24.6	27.4	26.2	22.9	20.7	22.0	28.2	16.6	18.3	23.9	21.4	22.5
55-64 years	10.7	14.1	12.6	7.0	6.4	6.7	10.5	9.8	9.9	8.5	10.1	9.4
65+ years	11.2	8.8	9.9	2.0	1.3	1.7	6.0	13.0	12.0	5.4	7.8	6.7
Severe/Profound												
0-14 years	7.9	9.6	9.2	3.6	11.9	7.9	12.5	3.4	3.9	6.7	5.3	5.6
15-21 years	17.1	14.3	15.2	12.1	16.4	14.3	8.4	10.9	10.8	13.0	12.1	12.3
22-39 years	50.0	52.0	51.3	61.9	44.3	52.8	37.7	56.0	54.9	53.5	54.0	53.9
40-54 years	14.8	14.6	14.7	18.0	18.1	18.0	23.2	18.2	18.5	18.0	17.7	17.8
55-64 years	5.9	5.7	5.8	3.5	8.5	6.1	10.5	6.2	6.4	5.6	6.4	6.3
65+ years	4.3	3.6	3.8	0.8	0.9	0.8	7.7	5.3	5.4	3.2	4.5	4.3
<b>Related Conditions Only</b>												
0-14 years	13.4	0.0	6.8	0.0	13.4	11.9	0.0	0.0	0.0	11.8	5.7	7.7
15-21 years	0.0	33.7	16.5	0.0	8.3	7.3	0.0	0.0	0.0	0.0	17.2	11.6
22-39 years	41.3	10.5	26.3	0.0	34.7	30.8	0.0	0.0	0.0	36.6	19.1	24.7
40-54 years	10.4	0.0	5.3	100.0	13.5	23.2	0.0	32.4	32.4	20.6	11.2	14.2
55-64 years	13.0	33.9	23.2	0.0	30.1	26.7	0.0	0.0	0.0	11.5	26.6	21.7
65+ years	21.9	21.9	21.9	0.0	0.0	0.0	0.0	67.6	67.6	19.4	20.3	20.0
<b>Total MR and RC</b>												
0-14 years	7.2	5.6	6.3	1.2	8.0	4.3	8.9	3.5	3.9	4.2	4.8	4.6
15-21 years	10.1	9.1	9.5	10.0	17.4	13.4	8.3	9.8	9.7	9.9	11.2	10.8
22-39 years	43.5	46.6	45.3	59.7	46.4	53.6	40.0	54.8	53.7	52.0	51.5	51.6
40-54 years	20.9	21.3	21.1	21.5	19.5	20.6	25.3	17.9	18.5	21.8	18.9	19.8
55-64 years	9.1	10.7	10.0	5.9	7.6	6.7	10.5	6.9	7.2	7.5	7.8	7.7
65+ years	9.1	6.7	7.7	1.6	1.1	1.4	7.0	7.0	7.0	4.8	5.8	5.5
<p><b>Notes:</b> Borderline/Mild/Moderate category includes 2.5% of estimated population which was reported to be mentally retarded, but whose level of retardation was not reported. The "related conditions only" category is based on only 33 (of 3,618 total) sample members.</p>												

**TABLE 16. Age Distribution of Residents of Mental Retardation Facilities by Level of Retardation and Certification Status**

	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified			15- res.	16+ res.	Total
	15- res.	16+ res.	Total	15- res.	16+ res.	Total			
<b>Mentally Retarded</b>									
Borderline/Mild/Moderate									
0-14 years	1.5	3.6	3.0	3.1	4.0	3.5	2.6	3.8	3.3
15-21 years	9.1	6.6	7.3	7.9	13.0	10.1	8.2	9.4	8.9
22-39 years	49.2	50.2	49.9	52.3	44.1	48.6	51.4	47.6	49.2
40-54 years	27.3	19.5	21.8	22.5	23.8	23.1	23.9	21.4	22.5
55-64 years	7.8	9.8	9.3	8.8	10.4	9.5	8.5	10.1	9.4
65+ years	5.1	10.2	8.7	5.5	4.7	5.2	5.4	7.8	6.7
Severe/Profound									
0-14 years	2.7	4.7	4.5	9.1	9.9	9.5	6.7	5.3	5.6
15-21 years	8.1	10.9	10.7	16.0	20.8	18.1	13.0	12.1	12.3
22-39 years	60.3	54.6	55.1	49.4	49.4	49.4	53.5	54.0	53.9
40-54 years	19.2	18.4	18.5	17.2	12.2	15.0	18.0	17.7	17.8
55-64 years	8.4	6.6	6.7	4.0	5.3	4.5	5.6	6.4	6.3
65+ years	1.3	4.8	4.5	4.4	2.3	3.5	3.2	4.5	4.3
<b>Related Conditions Only</b>									
0-14 years	0.0	0.0	0.0	14.4	12.2	13.2	11.8	5.7	7.7
15-21 years	0.0	16.3	14.1	0.0	18.2	9.9	0.0	17.2	11.6
22-39 years	100.0	17.1	28.4	23.0	21.3	22.1	36.6	19.1	24.7
40-54 years	0.0	21.1	18.2	25.0	0.0	11.4	20.6	11.2	14.2
55-64 years	0.0	24.1	20.8	14.0	29.3	22.3	11.5	26.6	21.7
65+ years	0.0	21.4	18.5	23.6	18.9	21.1	19.4	20.3	20.0
<b>Total MR and RC</b>									
0-14 years	2.0	4.4	4.0	5.2	6.1	5.6	4.2	4.8	4.6
15-21 years	8.6	9.8	9.7	10.4	15.6	12.8	9.9	11.2	10.8
22-39 years	54.0	53.3	53.4	51.0	45.5	48.5	52.0	51.5	51.6
40-54 years	23.8	18.7	19.5	20.8	19.6	20.3	21.8	18.9	19.8
55-64 years	8.0	7.5	7.6	7.2	9.0	8.0	7.5	7.8	7.7
65+ years	3.5	6.3	5.8	5.4	4.2	4.8	4.8	5.8	5.5
<p><b>Notes.</b> Borderline/Mild/Moderate category includes 2.5% of estimated population which was reported to be mentally retarded, but whose level of retardation was not reported. The "related conditions only" category is based on only 33 of 3,618 total sample members.</p>									

**TABLE 17. Age Distribution of Residents of Mental Retardation Facilities by Level of Mental Retardation and Facility Size**

	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>Mentally Retarded</b>							
Borderline/Mild/Moderate							
0-14 years	7.0	2.0	7.7	4.3	3.4	3.5	3.3
15-21 years	12.1	8.2	12.2	12.5	10.1	8.2	8.9
22-39 years	52.9	51.3	44.2	51.4	57.4	50.8	49.2
40-54 years	17.5	25.1	17.7	20.6	17.8	21.1	22.5
55-64 years	5.1	9.3	10.0	7.9	6.1	8.0	9.4
65+ years	5.5	4.2	8.1	3.4	5.2	8.4	6.7
Severe/Profound							
0-14 years	9.1	4.5	13.6	4.2	3.5	3.8	5.6
15-21 years	17.2	9.0	15.7	12.6	11.3	9.2	12.3
22-39 years	54.1	52.8	40.3	57.0	58.7	48.4	53.9
40-54 years	12.3	23.3	11.0	19.0	17.7	23.0	17.8
55-64 years	3.5	7.6	9.3	5.5	5.3	8.5	6.3
65+ years	3.7	2.8	9.9	1.6	3.6	7.1	4.3
<b>Related Conditions Only</b>							
0-14 years	19.4	0.0	0.0	16.5	0.0	–	7.7
15-21 years	0.0	0.0	15.8	25.0	0.0	–	11.6
22-39 years	50.4	15.0	7.9	42.7	0.0	–	24.7
40-54 years	15.1	29.1	10.7	15.8	0.0	–	14.2
55-64 years	0.0	29.6	49.2	0.0	0.0	–	21.7
65+ years	15.1	26.2	16.4	0.0	100.0	–	20.0
<b>Total MR and RC</b>							
0-14 years	7.0	2.0	7.7	4.3	3.4	3.5	4.6
15-21 years	12.1	8.2	12.2	12.5	10.1	8.2	10.8
22-39 years	52.9	51.3	44.2	51.4	57.4	50.8	51.6
40-54 years	17.5	25.1	17.7	20.6	17.8	21.1	19.8
55-64 years	5.1	9.3	10.0	7.9	6.1	8.0	7.7
65+ years	5.5	4.2	8.1	3.4	5.2	8.4	5.5
<p><b>Notes.</b> Borderline/Mild/Moderate category includes 2.5% of estimated population which was reported to be mentally retarded, but whose level of retardation was not reported. The “related conditions only” category is based on only 33 of 3,618 total sample members.</p>							

## **Activities of Daily Living (ADLs)**

Table 18, Table 19 and Table 20 present estimates of the proportion of residents with mental retardation and related conditions who were reported to be able to perform activities of daily living independently, with special equipment, only with assistance or supervision from other persons, or not at all. Estimates are presented by type of operation (Table 18), ICF-MR certification status (Table 19) and facility size (Table 20).

**Bathing/showering.** An estimated 39.1% of persons with mental retardation and related conditions in mental retardation facilities were reported to be able to bathe or shower independently. Large differences were noted within all three groupings of facilities. The group of residents reported as least likely to be able to bathe or shower independently were the residents of public institutions (22.2%); most likely were the residents of small nonprofit facilities (63.2%). Substantial differences were evident between large and small facilities generally (57.0% and 31.5%, respectively). Similar large differences were noted between ICF-MR certified facilities (28.4%) and non-certified facilities (57.7%). Generally the larger the facility, the smaller the proportion of its residents indicated as being able to bathe or shower independently. The primary exception was among the very smallest facilities (6 or fewer residents), which had somewhat higher proportions of dependent residents as indicated by all ADL ratings (and related impairments) than did facilities of 7-15 residents.

**Dressing.** An estimated 45.6% of residents with mental retardation and related conditions were reported to be able to dress themselves without assistance or supervision. Substantial differences were noted in the proportion of residents in different types of facilities able to dress themselves independently. Only 27.3% of residents of public institutions were reported to dress with assistance, as compared with 67.7% of small nonprofit facility residents. Rates of independent dressing were much lower in ICFs-MR than in non-certified facilities (36.2% versus 62.2%), but were not appreciably different between small ICFs-MR and small non-certified group homes (61.8% and 63.1%, respectively). With the exception of the smallest facilities (6 or fewer residents), which had somewhat more impaired populations than the 7-15 resident group homes, as facility size increased reported independence in dressing decreased, from 68.4% of residents of facilities with 7-15 residents to 25.9% of residents of facilities with 800 or more residents.

**Toileting.** Over two-thirds of the residents with mental retardation and related conditions were reported to be able to use the toilet independently. Over half the residents of all types of facilities were reported to be independent in toileting, ranging from 51.7% of public institution residents to 90.1% of residents of small, private nonprofit group homes. The difference between ICFs-MR and noncertified facilities in the proportion of residents independent in toileting was also substantial (59.1% and 83.7%). However, no differences were noted between small ICFs-MR and small noncertified group homes (86.6% and 85.7%, respectively). An estimated 9.4% of residents were reported to not use the toilet at all. Proportions ranged from 16.1% of public institution residents to 1.2% of small, private nonprofit facility residents. An estimated 2.1% of small facility and 12.5% of large facility

residents were reported not to use the toilet, with the highest proportion in facilities of 300 or more residents (14.3%).

**Getting in and out of bed.** An estimated 80.3% of residents with mental retardation and related conditions were reported to be able to get in and out of bed independently. Reported rates varied from 68.9% of public institution residents to 96.6% of small, private nonprofit facility residents. Three-quarters (74.4%) of large facility residents and 94.0% of small facility residents were reported to be able to get out of bed independently. While the proportion of all ICF-MR residents able to get out of bed independently was consistently lower than the proportion of noncertified facility residents (74.3% and 90.7%, respectively), a slightly higher proportion of residents of small ICFs-MR than residents of small noncertified group homes were reported to be able to get out of bed independently (96.6% and 92.7%, respectively). An estimated 4.6% of mental retardation facilities residents were reported to not assist in getting themselves out of bed even with the support of another person or of equipment. The highest proportion of the individuals who were reported to be totally dependent in getting out of bed was in large public institutions (7.0%); the lowest proportion was in small private nonprofit facilities (.5%).

**Feeding self.** An estimated 77.2% of residents with mental retardation and related conditions were reported able to feed themselves without assistance. Proportions of residents eating independently ranged from 64.6% in state institutions to 92.9% in small, private nonprofit facilities. Large facility residents were reported to be independent in eating considerably less often than were small facility residents (71.5% and 90.7%, respectively). ICF-MR residents were considerably less often reported as independent than were non-ICF-MR residents (70.1% and 89.5%, respectively), although little difference was noted among residents of small ICF-MR and small non-ICF-MR facilities (88.9% and 91.6%). An estimated 6.6% of mental retardation facility residents were reported to be unable to feed themselves even with the supervision or assistance of another person or equipment. This group included 11.4% of public institution residents, 9.2% of ICF-MR residents, and 8.9% of larger facility residents (i.e., 16 or more residents), but only 1.3% of residents of facilities with 15 or fewer residents.

**TABLE 18. Activities of Daily Living of Residents of Mental Retardation Facilities by Facility Operation**

Activity	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public					
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total
<b>Bathing or Showering</b>												
No difficulty w/o help	52.5	38.6	44.2	62.3	52.2	57.6	44.7	22.2	23.9	57.0	31.5	39.1
Received assistance or supervision	47.5	61.4	55.8	37.7	47.8	42.3	55.3	77.8	76.1	43.0	68.5	60.9
Uses special equipment/no other assistance	0.0	0.0	0.0	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
<b>Dressing</b>												
No difficulty w/o help	56.3	50.9	53.1	67.7	59.0	63.7	57.1	27.3	29.6	62.6	38.4	45.6
Received assistance or supervision	43.5	49.1	46.8	32.3	40.8	36.2	42.1	72.7	70.4	37.2	61.5	54.3
Uses special equipment/no other assistance	0.2	0.0	0.1	0.0	0.2	0.1	0.8	0.0	0.2	0.2	0.0	0.1
<b>Using the Toilet</b>												
No difficulty w/o help	81.6	70.5	75.0	90.1	75.9	83.5	79.8	51.7	53.9	86.0	60.4	68.1
Received assistance or supervision	16.3	20.2	18.6	8.4	18.9	13.2	12.5	32.2	30.6	11.5	27.0	22.4
Uses special equipment/no other assistance	0.2	0.2	0.2	0.3	0.0	0.2	0.8	0.1	0.2	0.4	0.1	0.2
Did not do at all	1.9	9.1	6.2	1.2	5.3	3.1	6.8	16.1	15.4	2.1	12.5	9.4
<b>Getting In/Out of Bed</b>												
No difficulty w/o help	92.6	78.9	84.4	96.6	86.3	91.9	85.9	68.9	70.2	94.0	74.4	80.3
Received assistance or supervision	6.2	14.2	10.9	2.8	11.6	6.8	9.5	24.0	22.9	4.7	19.5	15.1
Uses special equipment/no other assistance	0.0	0.2	0.1	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.1
Did not do at all	1.3	6.7	4.5	0.5	2.1	1.2	4.6	7.0	6.8	1.3	6.0	4.6
<b>Feeding Self</b>												
No difficulty w/o help	89.2	78.7	82.9	92.9	84.4	89.0	84.7	64.6	66.2	90.7	71.5	77.2
Received assistance or supervision	9.5	14.5	12.5	6.4	11.6	8.8	9.1	23.4	22.3	7.8	19.2	15.8
Uses special equipment/no other assistance	0.0	0.4	0.2	0.2	0.1	0.2	0.5	0.6	0.6	0.2	0.4	0.4
Did not do at all	1.3	6.5	4.4	0.4	3.9	2.0	5.6	11.4	11.0	1.3	8.9	6.6
<b>Walking Across Room</b>												
No difficulty w/o help	89.3	76.2	81.5	94.0	82.5	88.7	83.4	66.0	67.4	91.2	71.4	77.3
Received assistance or supervision	5.7	8.5	7.4	3.9	6.4	5.0	8.5	11.3	11.1	5.0	9.8	8.4
Uses special equipment/no other assistance	1.0	1.2	1.1	0.7	1.8	1.2	1.9	1.2	1.3	0.9	1.3	1.2
Did not do at all	4.0	14.1	10.0	1.5	9.2	5.0	6.3	21.4	20.3	2.9	17.5	13.2

**TABLE 19. Activities of Daily Living of Residents of Mental Retardation Facilities by Certification Status**

Activity	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified			15-res.	16+ res.	Total
	15-res.	16+ res.	Total	15-res.	16+ res.	Total			
<b>Bathing or Showering</b>									
No difficulty w/o help	53.9	23.8	28.4	58.5	56.9	57.7	57.0	31.5	39.1
Received assistance or supervision	46.0	76.2	71.6	41.5	43.1	42.3	43.0	68.5	60.9
Uses special equipment/no other assistance	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
<b>Dressing</b>									
No difficulty w/o help	61.8	31.6	36.2	63.1	61.1	62.2	62.6	38.4	45.6
Received assistance or supervision	38.0	68.4	63.8	36.8	38.7	37.7	37.2	61.5	54.3
Uses special equipment/no other assistance	0.2	0.0	0.0	0.1	0.2	0.2	0.2	0.0	0.1
<b>Using the Toilet</b>									
No difficulty w/o help	86.6	54.2	59.1	85.7	81.2	83.7	86.0	60.4	68.1
Received assistance or supervision	12.2	31.1	28.2	11.2	13.4	12.1	11.5	27.0	22.4
Uses special equipment/no other assistance	0.2	0.1	0.1	0.4	0.0	0.2	0.4	0.1	0.2
Did not do at all	1.0	14.6	12.5	2.6	5.5	3.9	2.1	12.5	9.4
<b>Getting In/Out of Bed</b>									
No difficulty w/o help	96.6	70.3	74.3	92.7	88.2	90.7	94.0	74.4	80.3
Received assistance or supervision	2.6	23.3	20.2	5.7	7.0	6.3	4.7	19.5	15.1
Uses special education/no other assistance	0.2	0.0	0.0	0.0	0.2	0.1	0.0	0.1	0.1
Did not do at all	0.6	6.4	5.5	1.6	4.6	2.9	1.3	6.0	4.6
<b>Feeding Self</b>									
No difficulty w/o help	88.9	66.8	70.1	91.6	86.9	89.5	90.7	71.5	77.2
Received assistance or supervision	10.4	21.8	20.1	6.5	10.7	8.4	7.8	19.2	15.8
Uses special equipment/no other assistance	0.6	0.6	0.6	0.0	0.0	0.0	0.2	0.4	0.4
Did not do at all	0.2	10.8	9.2	1.9	2.4	2.1	1.3	8.9	6.6
<b>Walking Across Room</b>									
No difficulty w/o help	92.8	66.4	70.5	90.3	87.7	89.2	91.2	71.4	77.3
Received assistance or supervision	4.7	11.4	10.4	5.2	4.4	4.8	5.0	9.8	8.4
Uses special equipment/no other assistance	1.1	1.5	1.4	0.9	0.8	0.8	0.9	1.3	1.2
Did not do at all	1.3	20.7	17.7	3.6	7.1	5.2	2.9	17.5	13.2

**TABLE 20. Activities of Daily Living of Residents of Mental Retardation Facilities by Facility Size**

Activities	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>Bathing or Showering</b>							
No difficulty w/o help	50.1	62.3	48.1	30.5	21.1	26.4	39.1
Received assistance or supervision	49.9	37.6	51.9	69.5	78.9	73.6	60.9
Uses special equipment/no other assistance	0.0	0.1	0.9	0.0	0.0	0.0	0.0
<b>Dressing</b>							
No difficulty w/o help	55.2	68.4	55.3	40.9	27.3	25.9	45.6
Received assistance or supervision	44.6	31.5	44.7	59.0	72.7	74.1	54.3
Uses special education/no other assistance	0.2	0.2	0.0	0.2	0.0	0.0	0.1
<b>Using the Toilet</b>							
No difficulty w/o help	80.8	90.0	75.0	59.4	50.6	57.8	68.1
Received assistance or supervision	16.7	7.6	17.3	26.4	35.0	27.8	22.4
Uses special equipment/no other assistance	0.2	0.5	0.0	0.1	0.2	0.0	0.2
Did not do at all	2.3	2.0	7.7	14.1	14.3	14.3	9.4
<b>Getting In/Out of Bed</b>							
No difficulty w/o help	92.8	94.9	85.4	70.7	69.2	74.0	80.3
Received assistance or supervision	5.6	4.0	11.8	21.1	24.6	18.3	15.1
Uses special equipment/no other assistance	0.0	0.1	0.2	0.0	0.1	0.0	0.1
Did not do at all	1.7	1.0	2.7	8.2	6.1	7.7	4.6
<b>Feeding Self</b>							
No difficulty w/o help	88.5	92.4	83.8	69.2	64.6	69.0	77.2
Received assistance or supervision	9.8	6.3	11.3	20.0	24.6	19.3	15.8
Uses special equipment/no other assistance	0.3	0.1	0.3	0.4	0.5	0.8	0.4
Did not do at all	1.5	1.2	4.6	10.4	10.3	10.9	6.6
<b>Walking Across Room</b>							
No difficulty w/o help	89.1	92.8	82.2	68.6	65.7	70.3	77.3
Received assistance or supervision	6.0	4.3	6.9	10.1	11.5	10.7	8.4
Uses special equipment/no other assistance	0.8	1.0	1.4	1.1	1.9	0.0	1.2
Did not do at all	4.1	2.0	9.6	20.2	20.9	19.0	13.2

**Walking across room.** Most residents with mental retardation and related conditions were reported to be able to walk across a room without physical assistance from other people or equipment. Another 12% were reported able to do so with the aid of equipment, but without assistance from another person. Ambulation with the assistance of another person (independent with or without equipment) was reported for two-thirds (67.2%) of the residents of public institutions and 94.7% of the residents of small, private nonprofit facilities. Residents of large facilities were much less likely to be reported as ambulatory without personal assistance than were residents of small facilities (72.7% and 92.1%, respectively). Residents of ICFs-MR were less likely to be ambulatory than residents of noncertified facilities (71.9% and 90.0%, respectively), except again that small ICF-MR and small noncertified facility residents were reported to be very similar on this variable (93.9% and 91.2%, respectively). The proportion of residents reported to be unable to walk across the room even with the assistance of another person or equipment was highest among public institution residents (21.4%), large facility residents (17.5%), especially facilities of 76 or more residents (20.5%), and ICFs-MR (17.7%). Proportions of these functionally nonambulatory residents were lowest among small facilities generally (2.9%) and especially small ICF-MR certified facilities (1.3%).

### **Instrumental Activities of Daily Living (IADLs)**

Table 21, Table 22 and Table 23 present estimates of the proportion of persons with mental retardation and related conditions in mental retardation facilities who were reported to perform different instrumental activities of daily living independently (with or without difficulty), with help, or not at all. Estimates are presented by type of operation of facilities (Table 21), ICF-MR certification status (Table 22), and facility size (Table 23).

**Use of telephone.** An estimated 25.8% of residents of mental retardation facilities were reported to use a telephone independently. Another 25.5% were reported to use a telephone with assistance. Independent telephone use was lower in larger facilities (16+ residents) than in smaller facilities (20.5% and 38.5%, respectively). It was lowest in large public facilities (8.5%) and highest in small, private for profit facilities (42.3%). ICFs-MR had a much lower proportion of people reported to use the telephone independently than did non-certified facilities (15.6% and 41.6%, respectively), but no difference was found between small ICFs-MR and small noncertified facilities (38.7% and 38.5%, respectively). An estimated 48.7% of persons with mental retardation and related conditions were reported not to use a telephone at all, even with "help of any kind." By far the largest proportion of persons never using the telephone lived in large public facilities (73.9%); the smallest proportion lived in small, private nonprofit facilities (23.9%). While a much larger proportion of ICF-MR residents were reported to never use a telephone than residents of noncertified facilities (61.0% and 29.8%, respectively), the proportions were essentially equal for small facilities with and without ICF-MR certification (28.8% and 27.7%, respectively).

**Managing money.** An estimated 11.4% of persons with mental retardation and related conditions in mental retardation facilities were reported to manage their money

("such as keeping track of expenses or paying bills") without assistance. Persons reported independent in managing their money included 16.6% of smaller facility residents and 9.3% of residents of larger facilities (16+ residents). The smallest proportion of residents independently managing their money was reported by public institutions (5.1%); the largest was in small, for profit facilities (26.9%). An estimated 27.8% of all residents were reported to manage money with assistance. Substantial differences were reported between larger and smaller facilities (21.3% and 43.2%, respectively). An estimated 60.8% of residents did not participate in money management activities. Large public facilities had the highest proportion of residents who were not involved in either independent or assisted money management (81.2%), while small private facilities had the lowest (38.9%). ICF-MR residents were much less likely than non-ICF-MR facility residents to be involved in managing their own finances (70.8% and 45.5%, respectively), although no differences were noted between small ICF-MR and small non-ICF-MR facilities (40.9% and 40.0%, respectively).

***Shopping for personal items.*** An estimated 15.6% of residents of mental retardation facilities were reported to "shop for personal items such as toilet items or medicines" without help. Proportions of people reported to shop for personal items independently ranged from 6.0% of residents of large public facilities to 31.3% of residents of small for profit facilities. An estimated 12.3% of all larger facility residents and 23.6% of all small facility residents were reported to be independent in this activity. ICF-MR residents were considerably less likely to be independent in shopping for personal items than residents of non-ICF-MR facilities (8.7% and 26.4%, respectively). An estimated 45.6% of all residents of mental retardation facilities were reported not to engage in shopping for personal items at all, even with assistance. Proportions of residents reported not to be involved in shopping for personal items ranged from 69.1% of large government facility residents to 20.1% of small, private nonprofit residents. Rates of independent and assisted involvement in shopping for personal items were considerably higher in private nonprofit facilities (75.7%), than in private for profit (63.7%), or publicly operated facilities (34.1%). A much smaller proportion of ICF-MR residents than non-ICF-MR residents were involved in shopping for personal items independently or with assistance (42.7% and 72.4%, respectively). However, no differences were found between small ICFs-MR and small noncertified facilities in the proportion of residents involved in shopping for personal items (76.3% and 75.6%, respectively).

***Use, of personal or public transportation.*** A substantial minority (17.3%) of residents of mental retardation facilities were reported to be independent in getting around the community by using personal or using public transportation. Presumably few sample members used personal transportation "to get around the community," but the use of personal and public transportation was combined in the NMES instrument. Persons reported to use personal or public transportation to get around the community included 12.8% of residents of larger facilities (16+ residents) and 28.0% of residents of small facilities. Lowest rates of independent use of personal or public transportation to get around the community were reported for residents of larger public facilities (5.8%); the highest rates were reported for residents of small private for profit facilities. ICF-MR

residents were much less likely to be able to use private or public transportation independently than residents of non-certified facilities (9.3% and 29.6%, respectively).

**TABLE 21. Performance of Instrumental Activities of Daily Living of Residents of Mental Retardation Facilities by Facility Operation**

IADL	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public					
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total
<b>Using Telephone</b>												
Independent	42.3	35.8	38.1	38.2	36.0	37.2	27.3	8.5	9.9	38.5	20.5	25.8
With help	27.4	26.8	27.0	37.9	29.6	34.3	31.5	17.6	18.6	33.4	22.1	25.5
Not at all	30.3	37.4	34.8	23.9	34.4	28.4	41.2	73.9	71.5	28.0	57.4	48.7
<b>Managing Money</b>												
Independent	26.9	16.9	20.5	9.4	11.0	10.1	17.3	5.1	6.0	16.6	9.3	11.4
With help	33.5	30.5	31.6	52.4	32.1	43.6	29.7	13.7	14.8	43.2	21.3	27.8
Not at all	39.6	52.7	47.9	38.2	56.9	46.3	53.1	81.2	79.2	40.3	69.4	60.8
<b>Shopping for Personal Items</b>												
Independent	31.3	18.8	23.3	18.2	23.1	20.3	24.6	6.0	7.4	23.6	12.3	15.6
With help	38.7	41.4	40.4	61.7	47.2	55.4	50.5	24.9	26.8	52.2	33.1	38.7
Not at all	30.1	39.9	36.3	20.1	29.7	24.3	24.9	69.1	65.9	24.2	54.6	45.6
<b>Using Own or Public Transportation</b>												
Independent	34.9	22.2	26.8	24.9	21.2	23.3	20.1	5.8	6.9	28.0	12.8	17.3
With help	40.9	42.3	41.6	50.0	48.1	54.8	69.9	38.4	40.7	54.1	41.1	44.9
Not at all	24.2	35.5	31.4	15.2	30.7	22.0	10.1	55.8	52.5	17.9	46.1	37.8

An estimated 37.8% of residents of mental retardation facilities were reported not to get around the community "at all," with or without assistance by using personal or public transportation. The highest proportion of these individuals were residents of public institutions (55.8%), the lowest proportions were in small public facilities (10.1%) and small, private nonprofit facilities (15.2%). There was a major difference in the proportion of residents of large (16+ residents) and small facilities who got around the community by driving or using public transportation independently or with assistance (46.1% and 17.9%, respectively). ICF-MR residents were much more likely than residents of noncertified facilities to not use private or public transportation to get around town either independently or with help (48.0% and 22.0%, respectively). Differences between small ICFs-MR and non-ICFs-MR were negligible (16.8% and 18.4%, respectively).

**TABLE 22. Performance of Instrumental Activities of Daily Living of Residents of Mental Retardation Facilities by Certification Status**

IADL	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified					
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
<b>Using Telephone</b>									
Independent	38.7	11.4	15.6	38.5	44.9	41.6	38.5	20.5	25.8
With help	32.6	21.7	23.4	33.8	23.1	28.6	33.5	22.1	25.5
Not at all	28.8	66.9	61.0	27.7	32.0	29.8	28.0	57.4	48.7
<b>Managing Money</b>									
Independent	12.5	5.4	6.5	18.4	19.5	18.9	16.6	9.3	11.4
With help	46.6	18.3	22.7	41.6	29.3	35.6	43.2	21.3	27.8
Not at all	40.9	76.2	70.8	40.0	51.2	45.5	40.3	69.4	60.8
<b>Shopping for Personal Items</b>									
Independent	20.3	6.6	8.7	25.1	27.8	26.4	23.6	12.3	15.6
With help	56.0	30.1	34.0	50.5	41.3	46.0	52.2	33.1	38.7
Not at all	23.7	63.4	57.3	24.4	30.9	27.6	24.2	54.6	45.6
<b>Using Own or Public Transportation</b>									
Independent	25.5	6.4	9.3	29.1	30.0	29.6	28.0	12.8	17.3
With help	57.7	39.9	42.7	52.5	44.2	48.5	54.1	41.1	44.9
Not at all	16.8	53.6	48.0	18.4	25.7	22.0	17.9	46.1	37.8

Notable differences were found among types of facilities in the extent to which assistance was provided to residents who were not independent to enable them to use private or public transportation. For example, of the residents of small for profit facilities who did not use private or public transportation independently (65.1% of all residents), only 62.8% were provided assistance which permitted them to engage in the activity. In contrast of the small private nonprofit facility residents who did not perform the activity independently (75.1% of all residents), 79.9% received assistance which permitted them to engage in the activity. Among small publicly operated facilities, 79.9% of residents did not perform the activity independently, but 87.5% of these individuals were reported to receive assistance which permitted them to engage in the activity.

TABLE 23. Performance of Instrumental Activities of Daily Living by Residents of Mental Retardation Facilities by Facility Size							
IADL	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>Using Telephone</b>							
Independent	34.3	41.6	40.8	17.3	9.5	6.6	25.8
With help	30.8	35.3	25.4	25.8	14.6	26.6	25.5
Not at all	34.9	23.1	33.8	57.0	75.9	66.9	48.7
<b>Managing Money</b>							
Independent	12.3	19.6	17.7	6.6	5.3	5.2	11.4
With help	37.9	47.0	30.6	24.8	10.7	19.0	27.8
Not at all	49.8	33.4	51.8	68.6	83.9	75.8	60.8
<b>Shopping for Personal Items</b>							
Independent	19.6	26.4	24.0	9.7	6.8	4.0	15.6
With help	53.4	51.4	48.2	34.7	20.5	26.1	38.7
Not at all	27.0	22.2	27.8	55.6	72.7	69.8	45.6
<b>Uses Own or Public Transportation</b>							
Independent	22.1	32.2	26.3	10.4	5.9	3.3	17.3
With help	56.1	52.7	49.3	40.7	33.2	44.3	44.9
Not at all	21.8	15.1	24.4	48.9	60.9	52.4	37.8

### Disturbing Behavior and Moods

Table 24, Table 25 and Table 26 present estimates of the proportion of residents with mental retardation and related conditions exhibiting certain types of disturbing behavior “sometimes” or certain moods “frequently.” Estimates are presented by facility type (Table 24), ICF-MR certification status (Table 25), and facility size (Table 26). The statistics on disturbing behavior included all members of the sample. Questions regarding “moods” were not asked about residents with profound mental retardation. Unfortunately, the absence of frequency and severity indicators for these behaviors and moods makes interpretation of the statistics somewhat difficult.

**Gets upset/yells.** About half (51%) of residents were reported “sometimes” to get upset and yell. Considerable consistency was noted across the different facility types on this variable. An estimated 49.6% of residents of small facilities and 51.6% of residents of large facilities exhibited such behavior on occasion. Small differences were noted between ICF-MR residents and those of noncertified facilities (53.6% versus 47.1%) and

among facilities of substantially different sizes (50.1% in facilities of 6 or fewer residents and 56.4% in facilities with 800 or more residents).

***Tries to hurt others.*** An estimated 28.5% of residents were reported to sometimes attempt to hurt others physically. Again relatively consistent rates were reported across facility types. Private facilities noted rates somewhat lower than public facilities (24.5% and 33.9%, respectively). Large facilities noted rates somewhat higher than small facilities (29.9% and 25.2%). Higher proportions of ICF-MR residents were reported to be aggressive toward others than were residents of non-certified facilities (31.7% and 23.6%). Comparable statistics from a 1979 National Survey of Residential Facilities (NSRF) indicated that 16.3% of 965 private facility residents and 30.3% of 953 public facility residents attempted to injure others (Hill, Bruininks, & Lakin, 1983).

***Tries to hurt self.*** An estimated 22.4% of residents with mental retardation and related conditions were reported “sometimes” to try to hurt themselves. The proportion of residents attempting self-injury was somewhat higher in public facilities (28%) than in private facilities (20%). Differences between large and small facilities were relatively small (23.6% and 19.4%, respectively). Self-injurious behavior was reported to be more prevalent in ICFs-MR (25.5%) than in non-certified facilities (17.6%). Comparable statistics on self-injury in the 1979 NSRF (asking whether the individual has a “problem” with self-injurious behavior) indicated episodes of self-injury among 22% of the public facility sample and 11% of the private facility sample (Hill, Bruininks, & Lakin, 1983). The proportional increase in prevalence of self-injury in private facilities seems generally parallel with widespread movement of people with severe cognitive and behavioral impairments to community-based facilities since 1979, with the reported prevalence of self-injury among sample members with severe or profound mental retardation being 30% as compared with 17% for all other sample members. The overall increase in reported self-injury between the 1979 survey and the 1987 NMES was likely affected by the distinction between a “problem” with self-injury (as asked in the 1979 survey) and “sometimes exhibiting self injury” (as asked in NMES).

***Steals from others.*** An estimated 15.7% of residents were reported to steal from others on occasion. Reported rates showed considerable consistency across facility types and sizes. Among large facilities, stealing was reported for 16% of residents as compared with 15% for small facility residents. ICF-MR rates were 17%, as compared with 14% in noncertified facilities.

***Exposes self/Has problem sexual behavior.*** An estimated 12.4% of residents were reported to expose themselves or to exhibit other problem sexual behavior. While the proportion of residents exhibiting such behavior was slightly higher in public than in private facilities (14.7% and 10.7%), rates were very nearly the same in small and large facilities (12.1% and 12.5%). Slightly higher rates were reported in ICFs-MR than in noncertified facilities (13.7% and 10.5%).

***Gets lost/wanders.*** An estimated 14.4% of persons with mental retardation and related conditions were reported to have problems with wandering and/or getting lost. Rates of reported problems of this type were quite consistent across the various types and sizes of facility. The lowest reported rate was 11.1% in larger for profit facilities the highest was 16.8% in large public institutions.

***Unable to avoid dangerous things/places.*** An estimated 23.6% of residents were judged by careproviders to present problems because of their being unable to avoid dangerous things and/or places. This type of “problem behavior” was directly related to severity of cognitive impairment. Rates were higher in public institutions (31.8%), ICFs-MR (28.3%), and facilities with 300 or more residents (33.0%). Although there were differences between small and large facilities in this reported problem (18.9% and 25.6%, respectively), the degree of difference, which might be expected to be reflected in requirements for supervision, was not notably large. On the other hand, different residential environments likely pose different amounts of “dangerous things and/or places” for residents to avoid.

***Cries for no apparent reason.*** An estimated 12.5% of residents with mental retardation and related conditions were reported by careproviders to cry for long periods of time for no apparent reason. Differences in rates reported across facility types and sizes were relatively small.

## **Moods**

***Frequently worried/apprehensive.*** An estimated 31.4% of persons with mild to severe mental retardation or related conditions in mental retardation facilities were reported to be frequently worried or apprehensive. Reported rates were generally quite similar across facility types and sizes, although slightly higher among private facilities than public (32.7% and 28.0%). Estimated rates of frequent worry and apprehension were also consistent across facilities of different sizes. The notable exception was facilities with 800 or more residents, where the rate was less than one-half those of other facilities. The low reported estimate of apprehension among residents of these facilities may have been affected by the relatively small number of remaining sample members when residents with profound mental retardation (63% of the total) were excluded from the questions regarding mood.

***Frequently unresponsive or withdrawn.*** An estimated 18.5% of persons with mild to severe mental retardation or related conditions in mental retardation facilities were judged by their careproviders to be frequently unresponsive or withdrawn. Reported rates were generally similar across facility types with the lowest rates reported in small nonprofit facilities (14.6%) and the highest rates reported in public institutions (24.3%). Differences between ICFs-MR and other facilities were small.

***Frequently impatient or annoyed.*** An estimated 42.5% of persons with mild to severe mental retardation or related conditions in mental retardation facilities were

reported by their careproviders to be frequently impatient or annoyed. Reported rates were highest for public facilities especially the large ones (50.7%). They were lowest in nonprofit facilities especially the small ones (34.6%).

**Frequently suspicious.** An estimated 20.3% of persons with mild to severe mental retardation or related conditions were reported to frequently exhibit sense of suspicion. Reported rates were highest in the for profit facilities (26.4%) and lowest in the private nonprofit facilities (14.2%). Rates for public facilities (20.0%) were similar to the all facility average. Slightly higher rates were reported in small non-ICF-MR facilities than in small ICFs-MR (20.6% and 16.2%, respectively).

**TABLE 24. Percentage of Residents of Mental Retardation Facilities Exhibiting Disturbing Behavior or Moods by Facility Operation**

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public			15- res.	16+ res.	Total
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total			
<b>Disturbing Behavior</b>												
Gets upset/yells	50.9	46.0	47.8	48.1	51.0	49.4	52.4	54.5	54.3	49.6	51.6	51.0
Tries to hurt others physically	22.7	22.1	22.3	24.2	29.8	26.8	38.5	33.6	33.9	25.2	29.9	28.5
Tries to hurt self physically	17.5	15.6	16.3	19.6	20.8	20.2	24.4	28.4	28.1	19.4	23.6	22.4
Steals from others	12.6	16.5	15.1	16.6	11.8	14.3	15.8	17.2	17.0	15.0	16.0	15.7
Exposes self/has problem sexual behavior	12.0	10.6	11.1	10.9	9.3	10.2	17.8	14.5	14.7	12.1	12.5	12.4
Gets lost/wanders	14.2	11.1	12.2	11.5	15.6	13.4	13.5	16.8	16.5	12.7	15.1	14.4
Unable to avoid dangerous things/places	18.6	14.9	16.3	18.6	22.1	20.3	21.2	31.8	31.0	18.9	25.6	23.6
Cries for long period for no apparent reason	13.7	11.2	12.1	11.7	13.8	12.7	15.6	12.4	12.6	12.9	12.3	12.5
<b>Moods (excludes persons with profound mental retardation)</b>												
Frequently worried/apprehensive	32.9	33.3	33.2	33.9	29.9	32.2	24.8	28.5	28.0	32.7	30.6	31.4
Frequently unresponsive/withdrawn	21.4	16.5	18.4	14.6	15.0	14.7	17.7	24.3	23.4	17.5	19.2	18.5
Frequently impatient/annoyed	43.0	42.5	42.7	34.6	37.4	35.8	48.5	50.7	50.4	39.1	44.5	42.5
Frequently suspicious	23.6	28.3	26.4	16.5	11.2	14.2	17.1	20.4	20.0	19.3	20.9	20.3
<b>Notes.</b> For "disturbing behavior" respondents were asked if the subjects "sometimes disturb [respondent] or others by ..." (Items in Table). For "moods" respondents were asked if the subjects were...												

**TABLE 25. Percentage of Residents of Mental Retardation Facilities Exhibiting Disturbing Behavior or Moods by Facility Certification Status**

	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified			15-res.	16+ res.	Total
	15-res.	16+ res.	Total	15-res.	16+ res.	Total			
<b>Disturbing Behavior</b>									
Gets upset/yells	51.7	54.0	53.6	48.7	45.4	47.1	49.6	51.6	51.0
Tries to hurt others physically	26.5	32.7	31.7	24.7	22.5	23.6	25.2	29.9	28.5
Tries to hurt self physically	21.1	26.3	25.5	18.6	16.6	17.6	19.4	23.6	22.4
Steals from others	15.9	17.2	17.0	14.7	12.9	13.8	15.0	16.0	15.7
Exposes self/has problem sexual behavior	11.7	14.0	13.7	12.3	8.6	10.5	12.1	12.5	12.4
Gets lost/wanders	14.1	16.5	16.1	12.1	11.4	11.7	12.7	15.1	14.4
Unable to avoid dangerous things/places	21.9	29.4	28.3	17.6	15.5	16.6	18.9	25.6	23.6
Cries for long period for no apparent reason	12.5	13.7	13.6	13.0	8.7	10.9	12.9	12.3	12.5
<b>Moods (excludes persons with profound mental retardation)</b>									
Frequently worried/apprehensive	32.4	29.6	30.3	32.8	31.9	32.3	32.7	30.6	31.4
Frequently unresponsive/withdrawn	15.5	20.2	19.1	18.3	17.7	18.0	17.5	19.2	18.5
Frequently impatient/annoyed	44.7	47.7	47.0	36.8	39.8	38.3	39.1	44.5	42.5
Frequently suspicious	16.2	20.1	19.2	20.6	22.1	21.3	19.3	20.9	20.3
<p><b>Notes.</b> For "disturbing behavior" respondents were asked if the subjects "sometimes disturb [respondent] or others by ..." (Items in Table). For "moods" respondents were asked if the subjects were...</p>									

TABLE 26. Percentage of Residents of Mental Retardation Facilities Exhibiting Disturbing Behavior or Moods by Facility Size							
	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>Disturbing Behavior</b>							
Gets upset/yells	50.1	49.3	48.6	50.9	53.6	56.4	51.0
Tries to hurt others physically	22.8	27.1	26.0	30.6	32.3	31.2	28.5
Tries to hurt self physically	21.5	17.7	17.6	23.1	29.1	25.3	22.4
Steals from others	13.3	16.4	13.9	16.5	16.2	20.2	15.7
Exposes self/has problem sexual behavior	14.1	10.6	8.0	13.6	12.7	22.7	12.4
Gets lost/wanders	13.5	12.2	11.5	15.1	18.1	16.0	14.4
Unable to avoid dangerous things/places	21.4	17.0	16.4	24.4	33.5	31.2	23.6
Cries for long period for no apparent reason	14.6	11.6	9.8	16.0	10.5	15.2	12.5
<b>Moods (excludes persons with profound mental retardation)</b>							
Frequently worried/apprehensive	28.0	35.9	30.1	33.3	32.8	13.0	31.4
Frequently unresponsive/withdrawn	22.1	14.2	16.7	19.2	25.4	14.9	18.5
Frequently impatient/annoyed	39.1	39.2	41.1	45.3	47.1	55.3	42.5
Frequently suspicious	18.0	20.2	20.5	23.8	19.8	14.0	20.3
<small>Notes. For "disturbing behavior" respondents were asked if the subjects "sometimes disturb [respondent] or others by ..." (Items in Table). For "moods" respondents were asked if the subjects were...</small>							

### Medical Conditions by Age

Table 27, Table 28 and Table 29 present estimates of the prevalence of certain medical conditions among residents of mental retardation facilities. Estimates are presented by facility operation (Table 27), ICF-MR certification status (Table 28), and facility size (Table 29). Because of the association of these medical conditions with aging, separate estimates are presented for residents 64 years and younger and 55 years and older.

**Comatose.** None of the 3,618 members of the sample was reported to be comatose. Therefore, "1 comatose" was omitted from the following tables.

**Circulatory conditions.** Circulatory conditions, including present diagnoses of high blood pressure, hardening of arteries, or heart disease, or past occurrence of a stroke or heart attack, were reported for an estimated 11% of residents with mental retardation and related conditions. This overall rate is considerably less than the rate of 20.8% obtained in the 1985 National Health Interview Survey for the general population. As expected, circulatory conditions were considerably more common among those 55 and older than among the younger residents (31.4% and 7.8%, respectively). Because mental retardation facilities house a lower proportion of older persons than are found generally in the

population (e.g., 5.5% of mental retardation facility residents compared to 11.5% of the general population are 65 years or older), the somewhat lower rate of circulatory disorders among mental retardation facility residents might be expected. Rates of circulatory conditions were also somewhat higher for persons in the smaller facilities. These differences were noted despite a slightly older population in the larger facilities.

Circulatory conditions were reported to be slightly more common among the population of community based facilities (those with 15 or fewer residents) than among the populations of larger facilities for both the 54 years and younger group of residents (9.3% and 7.2%) and for those 55 and older (12.2% and 10.3%). Of all facilities those most likely to have residents with circulatory conditions were the very smallest, those with 6 or fewer residents (12.6% of residents). Facilities with the highest rates of circulatory conditions among residents 55 years and older (41%) were also the smallest facilities (6 or fewer residents). An estimated 38.3% of residents 55 and older in institutions of 300 or more residents were reported to have circulatory conditions. Circulatory conditions of residents were not significantly associated with ICF-MR certification status of the facilities in which they lived.

**Arthritis or rheumatism.** An estimated 4.6% of residents of mental retardation facilities were reported to have arthritis or rheumatism. This compares with an estimated 12% of the total U.S. population reported to experience limitations from arthritis and rheumatism in the 1985 National Health Interview Survey. The magnitude of this difference cannot be explained by the somewhat younger population of mental retardation facilities than with the population as a whole. The estimated prevalence of arthritis and rheumatism among persons 55 and younger in mental retardation facilities (2.2%) is less than half of the estimated U.S. prevalence of arthritis and rheumatism in the U.S. population of persons under 45 years (5.4%). It is likely that differences in reported prevalence were affected by the type of responses gathered in the National Health Interview Survey (self-report with some "self-diagnosis" likely) and the NMES (reports of care providers). As in the general population, within the NMES sample arthritis and rheumatism were very highly related to age, 6 times as great among those 55 and older than among those 54 and younger. The estimated prevalence of arthritis and rheumatism among persons 55 years and older in mental retardation facilities (20%) was also lower than the estimated 25.5% reported for the general population 45 years and older in the National Health Interview Survey. Some differences were noted in the prevalence of arthritis and rheumatism for different sizes and types of facilities, particularly among persons 55 years and older. Within the older age group, 31.4% of people in facilities of 6 or fewer residents and 25.3% of those in facilities of 15 and fewer residents were reported to have arthritis or rheumatism. This compared with 18% of older persons in facilities of 16 and more residents and only 15.3% in facilities of 76 or more residents. To some extent these differences were likely to be associated with the ability of residents to communicate about these conditions, and, perhaps, the extent to which careproviders are able to identify and report the symptoms of these conditions.

**Diabetes.** The estimated prevalence of diabetes among residents of mental retardation facilities was 2.0%. This compares with the National Health Interview Survey estimate of 2.6% of the U.S. population. However, there is a very high association of

diabetes with aging (e.g., the rate among 18-year olds is one-fifth the rate among 45-64 years and one-tenth the rate of people over 65), and the difference in estimated prevalence between mental retardation facilities and the general population can be attributed largely to the generally younger ages of mental retardation facility residents than members of the general population. Because of overall low rates of diabetes in the residential populations, cross facility comparisons have low precision of estimate. But in general, estimates showed consistency by facility type, ICF-MR certification status and facility size.

**Cancer.** Cancer was rare among the residents of mental retardation facilities. Again, the small number of individuals with cancer in the sample limited the precision of estimates across facility groups. The NMES estimated that 1.2% of residents in mental retardation facilities have some form of cancer. Estimated rates varied by age groupings from .4% of persons 54 and younger to 6.8% of persons 55 and older.

**Frequent constipation.** Frequent constipation was reported as a problem affecting 20.9% of residents of mental retardation facilities. Unlike the other medical conditions discussed above, frequent constipation was not associated with age. However, it is highly related to severity of mental impairment and more specifically associated with complications affecting amount of movement and the amount of upright positioning and mobility. In addition, severe mental impairments are often associated with neuromuscular disorders and abdominal muscle weaknesses which substantially contribute to constipation. Other contributors to constipation are relatively low fluid intake and general diet.

The strong association between frequent constipation and severity of impairment, especially for types or levels of Impairment associated with restrictions in movement and mobility, was evident in the reported chronic constipation of people in different types of residential facilities. Chronic constipation was noted for 31.6% of public institution residents and 30.6% of all public facility residents, which have much higher proportions of residents with profound mental retardation and mobility impairments. Much lower rates of chronic constipation were reported in private facility residents (15.4% private for profit and 10.6% of private nonprofit). Frequent constipation was noted for 26.4% of ICF-MR and 11.1% non-ICF-MR facility residents. Reported rates of chronic constipation ranged from 11.5% of the residents of small mental retardation facilities (15 or fewer residents) to 32.1% in facilities of 300 or more residents.

**Obesity.** About 13.2% of residents in mental retardation facilities were reported to be obese (“being very overweight”). Similar rates were reported for facilities of different types of operation: 14.9% in private for profit, 13.7% in private nonprofit and 12.0% in publicly operated facilities. Small facilities (15 or fewer residents) reported lower rates of obesity among residents 55 years and older than did larger facilities (12.7% and 17.3%, respectively). Residents in larger facilities who were 54 years or younger had lower rates of obesity than did residents of smaller facilities (11.7% and 15.4%). Smaller ICFs-MR had

considerably lower rates of obesity among their residents than smaller facilities without certification (10.6% and 17.3%).

**TABLE 27. Percentage of Residents of Mental Retardation Facilities with Selected Medical Conditions/Ailments by Facility Operation**

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public			15-res.	16+ res.	Total
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total			
<b>54 Years and Younger</b>												
Circulatory conditions	10.7	9.3	9.9	8.6	7.6	8.2	8.4	6.3	6.4	9.3	7.2	7.8
Arthritis or Rheumatism	1.7	2.0	1.8	2.4	3.1	2.7	3.3	2.0	2.1	2.3	2.2	2.2
Diabetes	0.5	1.7	1.2	2.2	1.6	1.9	2.9	0.9	1.1	1.8	1.2	1.4
Cancer	0.9	0.2	0.5	0.4	0.8	0.6	0.0	0.2	0.2	0.5	0.3	0.4
Frequent constipation	12.4	17.7	15.5	8.5	13.1	10.6	21.6	31.7	30.9	11.2	25.1	20.9
Obesity	14.6	14.4	14.5	15.4	11.2	13.5	18.0	10.9	11.4	15.4	11.7	12.8
<b>55 Years and Older</b>												
Circulatory conditions	34.7	31.9	33.0	32.8	18.8	25.8	30.9	32.4	32.3	33.4	30.6	31.4
Arthritis or Rheumatism	31.4	10.5	19.2	31.5	31.6	31.6	14.5	20.6	30.2	25.3	18.0	20.0
Diabetes	2.4	12.6	8.3	2.2	3.8	3.0	13.2	5.5	6.2	4.2	7.2	6.3
Cancer	4.8	2.0	3.2	3.9	4.7	4.3	7.0	10.4	10.1	4.9	7.5	6.8
Frequent constipation	11.6	17.0	14.7	10.6	10.7	10.7	28.9	28.5	28.6	14.2	23.2	20.7
Obesity	16.7	17.0	16.9	3.1	30.2	16.6	20.2	14.7	15.2	12.7	17.3	16.0
<b>All Residents</b>												
Circulatory conditions	15.1	13.2	14.0	10.5	8.6	9.6	12.4	9.9	10.1	12.2	10.3	10.9
Arthritis or Rheumatism	7.1	3.4	4.9	3.8	4.7	4.2	5.3	4.6	4.7	5.1	4.4	4.6
Diabetes	0.9	3.6	2.5	2.2	1.8	2.0	4.7	1.6	1.8	2.0	2.0	2.0
Cancer	1.6	0.5	1.0	0.6	1.1	0.9	1.2	1.6	1.6	1.0	1.3	1.2
Frequent constipation	12.2	17.6	15.4	8.7	12.9	10.6	22.9	31.3	30.6	11.5	24.8	20.9
Obesity	15.0	14.9	14.9	14.5	12.9	13.7	18.4	11.4	12.0	15.1	12.4	13.2
<p><b>Notes.</b> Entries are percent of residents within each group who have selected medical conditions/ailments. Columns do not add up to 100% because some residents had more than one condition and some had none. "Circulatory conditions" includes present high blood pressure, hardening of the arteries or heart disease or past stroke or heart attack.</p>												

**TABLE 28. Percentage of Residents of Mental Retardation Facilities with Selected Medical Conditions/Ailments by Facility Certification Status**

	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified			15- res.	16+ res.	Total
	15- res.	16+ res.	Total	15- res.	16+ res.	Total			
<b>54 Years and Younger</b>									
Circulatory conditions	8.5	6.9	7.1	9.7	8.0	8.9	9.3	7.2	7.8
Arthritis or Rheumatism	1.2	1.9	1.8	2.8	3.4	3.1	2.3	2.2	2.2
Diabetes	1.7	1.1	1.2	1.8	1.5	1.7	1.8	1.2	1.4
Cancer	0.8	0.2	0.3	0.4	0.7	0.5	0.5	0.3	0.4
Frequent constipation	11.5	29.4	26.6	11.0	10.7	10.9	11.2	25.1	20.9
Obesity	11.1	11.5	11.4	17.5	12.2	15.2	15.4	11.7	12.8
<b>55 Years and Older</b>									
Circulatory conditions	35.1	33.3	33.5	32.7	21.2	27.4	33.4	30.6	31.4
Arthritis or Rheumatism	28.3	19.5	20.7	23.9	12.8	18.8	25.3	18.0	20.0
Diabetes	4.9	6.8	6.5	3.8	8.5	6.0	4.2	7.2	6.3
Cancer	10.8	7.8	8.2	2.3	6.4	4.2	4.9	7.5	6.8
Frequent constipation	13.1	27.0	25.2	14.6	10.2	12.6	14.2	23.2	20.7
Obesity	6.7	18.0	16.5	15.4	14.9	15.2	12.7	17.3	16.0
<b>All Residents</b>									
Circulatory conditions	11.5	10.5	10.7	12.6	9.8	11.3	12.2	10.3	10.9
Arthritis or Rheumatism	4.3	4.3	4.3	5.5	4.6	5.1	5.1	4.4	4.6
Diabetes	2.1	1.9	1.9	2.0	2.4	2.2	2.0	2.0	2.0
Cancer	1.9	1.2	1.3	0.6	1.4	1.0	1.0	1.3	1.2
Frequent constipation	11.7	29.1	26.4	11.5	10.6	11.1	11.5	24.8	20.9
Obesity	10.6	12.4	12.1	17.3	12.6	15.2	15.1	12.4	13.2

**Notes.** Entries are percent of residents within each group who have selected medical conditions/ailments. Columns do not add up to 100% because some residents had more than one condition and some had none. "Circulatory conditions" includes present high blood pressure, hardening of the arteries or heart disease or past stroke or heart attack.

**TABLE 29. Percentage of Residents of Mental Retardation Facilities with Selected Medical Conditions/Ailments by Facility Size**

	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
<b>54 Years and Younger</b>							
Circulatory conditions	9.2	9.3	7.7	7.9	6.8	4.9	7.8
Arthritis or Rheumatism	2.7	1.9	2.9	2.2	2.2	0.9	2.2
Diabetes	1.0	2.3	2.0	1.1	0.8	1.2	1.4
Cancer	0.7	0.4	0.0	0.8	0.1	0.6	0.4
Frequent constipation	11.1	11.2	12.9	23.4	34.3	27.8	20.9
Obesity	17.6	13.7	12.5	10.5	13.0	8.5	12.8
<b>55 Years and Older</b>							
Circulatory conditions	41.0	28.8	23.8	27.1	36.7	41.6	31.4
Arthritis or Rheumatism	31.4	21.4	23.1	11.7	12.0	29.2	20.0
Diabetes	7.2	2.3	8.1	8.3	6.2	4.8	6.3
Cancer	6.5	3.9	5.1	6.5	11.3	7.5	6.8
Frequent constipation	21.3	9.9	20.2	21.3	27.2	26.4	20.7
Obesity	17.3	10.0	21.9	14.7	13.8	17.4	16.0
<b>All Residents</b>							
Circulatory conditions	12.6	11.9	10.6	10.1	10.2	10.9	10.9
Arthritis or Rheumatism	5.8	4.6	6.5	3.2	3.3	5.5	4.6
Diabetes	1.7	2.3	3.1	1.9	1.4	1.8	2.0
Cancer	1.3	0.9	0.9	1.4	1.3	1.7	1.2
Frequent constipation	12.2	11.0	14.2	23.1	33.5	27.5	20.9
Obesity	17.5	13.2	14.2	11.0	13.1	10.0	13.2

**Notes.** Entries are percent of residents within each group who have selected medical conditions/ailments. Columns do not add up to 100% because some residents had more than one condition and some had none. "Circulatory conditions" includes present high blood pressure, hardening of the arteries or heart disease or past stroke or heart attack.

## Use of Special Equipment and Devices

Table 30, Table 31 and Table 32 present estimates of the use of various kinds of special equipment and devices by residents of mental retardation facilities. Estimates are provided for type of facility operation (Table 30), ICF-MR certification status (Table 31), and facility size (Table 32).

**Corrective lenses.** An estimated 30.7% of residents of mental retardation facilities wore corrective lenses. Very substantial differences were noted between large and small facilities in the proportion of residents wearing corrective lenses (24.8% and 45.2%, respectively). Corrective lenses were least commonly worn by residents of large public facilities (15.8%). They were worn by 35.8% of large private facility residents, and 45.4% of small private facility residents. ICF-MR residents were considerably less likely than noncertified facility residents to wear lenses (23.5% and 41.6%).

**Hearing aids.** Hearing aids were worn by only an estimated 3.6% of residents of mental retardation facilities. They were more often worn by residents of small facilities (6.4%) than large facilities (2.5%).

**Special underwear or diapers.** An estimated 15.5% of residents of mental retardation facilities wore special underwear or diapers. Use was considerably higher among large facility residents (19.2%) than small facility residents (6.5%). Use was highest among public institution residents (23.9%) and lowest among residents of small, private nonprofit facilities (4.1%). An estimated 19.7% of ICF-MR residents and 9.2% of residents of noncertified facilities wore special underwear or diapers.

**Wheelchair.** An estimated 17.9% of all residents used wheelchairs. Use varied from 23.1% of residents in large facilities (29.8% in large public facilities) to 5.0% of residents in small facilities (3.6% in small private nonprofit facilities). ICF-MR residents were more likely to use wheelchairs (24.5%) than residents of noncertified facilities (7.9%), but residents of small ICF-MR facilities were less likely to use wheelchairs than residents of other small facilities (3.3% and 5.8%).

**Walker, cane or crutches.** An estimated 4.5% of residents of mental retardation facilities used walkers, canes or crutches to aid them in walking. No substantial differences were noted by type or size of facility, although small private for profit facilities did have higher utilization rates than other small facilities (5.7% and 2.8%). Large, private non-profit facilities had rates of utilization higher than other large facilities (6.4% and 4.5%). No differences were noted by ICF-MR status.

**Special dishes, cups, utensils.** An estimated 14.7% of persons with mental retardation and related conditions used adapted dishes, cups and/or utensils to aid them in feeding themselves. Persons in large facilities were considerably more likely than persons in small facilities to use adaptive utensils for eating (18.3% and 5.9%). Persons in large public institutions were most likely to use adaptive utensils for eating (24.0%). ICF-

MR residents were considerably more likely to be provided with special dishes, cups, and utensils than residents of noncertified facilities (20.2% and 6.3%).

***Mechanical devices for eating.*** Mechanical devices to assist residents with eating were rarely used. Only an estimated 1.1% of residents were provided with such equipment.

***Velcro fasteners or snaps for clothing.*** Velcro fasteners and snaps as an adaptation for persons who have difficulty with buttons and zippers were provided for an estimated 12.4% of residents of mental retardation facilities. These adaptations were most likely to be used in public facilities (17.9%), especially large public facilities (18.3%), and ICF-MR certified facilities (15.8%).

***Symbol systems/communication boards.*** Symbol systems or communication boards were used as the primary means of communication by only 1.0% of residents. (information was not gathered on the use of communication systems as supplements to primary use of spoken or signed language). Use of these alternative communication methods was similarly low among different categories of facilities, ranging from 1.3% in large facilities to 0.4% in small facilities, with no appreciable differences by type of facility.

***Shower seats or tub stools.*** An estimated 14.7% of persons with mental retardation and related conditions used seats or stools for bathing/showering. Such devices were more commonly provided in large facilities than small (18.0% and 6.6%, respectively). They were most commonly used by residents of large public facilities (21.7%).

***Portable toilets.*** Portable toilets were not frequently used by residents of mental retardation facilities (3.2%). They were more commonly used for residents of large facilities (4.2%), including 5.4% of residents of large public facilities and 5.1% of residents of large ICFs-MR. Portable toilets were used by only an estimated .5% of residents of small private facilities.

***Urinary catheter.*** Urinary catheters were rarely used by the residents of mental retardation facilities (1.0%). Estimated use was 1.4% or lower in each of the different sizes and types of facilities, except in public institutions with 800 or more residents (2.2%).

***Colostomy bag.*** Colostomy bags were very rarely used by residents of mental retardation facilities. Only .3% of residents were estimated to use colostomy bags, with no significant differences noted among facility types or sizes.

**TABLE 30. Percentage of Residents of Mental Retardation Facilities Using Various Types of Special Equipment and Devices of Facility Operation**

Equipment/Devices	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public					
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total
Corrective lenses	45.3	35.8	39.2	45.5	35.9	41.0	44.1	15.8	17.9	45.2	24.8	30.7
Hearing aid	5.5	2.6	3.7	6.6	3.0	4.9	8.5	2.3	2.7	6.4	2.5	3.6
Special underwear or diapers	8.0	14.9	12.4	4.1	11.3	7.5	12.0	23.9	23.0	6.5	19.2	15.5
Wheelchair	5.1	16.5	12.3	3.6	12.8	7.9	10.8	29.8	28.3	5.0	23.1	17.9
Walker, cane or crutches	5.7	5.1	5.3	2.9	6.4	4.5	2.6	4.1	4.0	3.9	4.8	4.5
Special dishes, cups, utensils	5.5	12.4	9.9	3.8	9.7	6.5	17.2	24.0	23.5	5.9	18.3	14.7
Mechanical devices for eating	0.1	0.9	0.6	0.0	1.5	0.7	0.0	1.7	1.6	0.1	1.5	1.1
Velcro fasteners or snaps	6.4	5.9	6.1	7.9	14.1	10.8	13.9	18.3	17.9	8.0	14.2	12.4
Symbol system/communication board as primary means of communication	0.0	1.6	1.0	0.5	1.0	0.7	1.3	1.2	1.2	0.4	1.3	1.0
Shower seat or tub stool	0.0	1.6	1.0	0.5	1.0	0.7	1.3	1.2	1.2	0.4	1.3	1.0
Portable toilet	0.6	4.1	2.8	0.4	0.9	0.6	2.7	5.4	5.2	0.7	4.2	3.2
Urinary catheter	0.1	1.3	0.9	0.9	1.2	1.0	0.0	1.1	1.1	0.5	1.2	1.0
Colostomy bag	0.1	0.7	0.5	0.3	0.0	0.1	0.0	0.2	0.2	0.2	0.3	0.3

**TABLE 31. Percentage of Residents of Mental Retardation Facilities Using Various Types of Special Equipment and Devices by ICF-MR Certification Status**

Equipment/Devices	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified			15-res.	16+ res.	Total
	15-res.	16+ res.	Total	15-res.	16+ res.	Total			
Corrective lenses	42.1	20.3	23.5	46.7	36.4	41.6	45.2	24.8	30.7
Hearing aid	7.1	2.6	3.3	6.1	2.2	4.2	6.4	2.5	3.6
Special underwear or diapers	4.6	22.3	19.7	6.3	11.1	9.2	6.5	19.2	15.5
Wheelchair	3.3	28.1	24.5	5.8	10.0	7.9	5.0	23.1	17.9
Walker, cane or crutches	3.6	4.8	4.6	4.0	4.8	4.4	3.9	4.8	4.5
Special dishes, cups, utensils	7.7	22.4	20.2	5.1	7.5	6.3	5.9	18.3	14.7
Mechanical devices for eating	0.0	1.9	1.6	0.1	0.4	0.3	0.1	1.5	1.1
Velcro fasteners or snaps	7.0	17.3	15.8	8.5	6.2	7.4	8.0	14.2	12.4
Symbol system/communication board as primary means of communication	0.4	1.6	1.4	0.4	0.3	0.4	0.4	1.3	1.0
Shower seat or tub stool	5.4	21.2	18.8	7.2	9.7	8.4	6.6	18.0	14.7
Portable toilet	0.6	5.1	4.5	0.8	1.9	1.3	0.7	4.2	3.2
Urinary catheter	0.7	1.4	1.3	0.4	0.6	0.5	0.5	1.2	1.0
Colostomy bag	0.2	0.4	0.3	0.2	0.2	0.2	0.2	0.3	0.3

**TABLE 32. Percentage of Residents of Mental Retardation Facilities Using Various Types of Special Equipment and Devices by Facility Size**

Equipment/Devices	Number of Residents in Facility						Total
	1-6 res.	7-15 res.	16-75 res.	76-299 res.	300-799 res.	800+ res.	
Corrective lenses	40.7	48.8	39.0	24.5	14.8	14.4	30.7
Hearing aid	6.8	6.2	2.7	2.2	1.7	5.2	3.6
Special underwear or diapers	11.1	2.9	13.1	20.7	23.6	18.9	15.5
Wheelchair	7.3	3.3	12.5	26.6	30.1	22.5	17.9
Walker, cane or crutches	5.9	3.1	6.6	4.3	4.5	1.5	4.5
Special dishes, cups, utensils	6.4	5.5	10.9	18.0	25.5	18.4	14.7
Mechanical devices for eating	0.1	0.0	0.8	1.9	1.8	1.1	1.1
Velcro fasteners or snaps	8.1	8.0	7.0	16.5	15.7	24.9	12.4
Symbol system/communication board as primary means of communication	0.5	0.4	0.9	1.8	0.9	2.2	1.0
Shower seat or tub stool	7.5	5.9	12.1	23.8	17.8	19.6	14.7
Portable toilet	0.9	0.7	2.5	4.9	5.1	4.9	3.2
Urinary catheter	0.5	0.5	1.0	1.2	1.0	2.2	1.0
Colostomy bag	0.0	0.3	0.7	0.1	0.2	0.0	0.3

## **Employment Status and Wages**

Table 33, Table 34, and Table 35 present estimates of the percentages of residents of mental retardation facilities working for pay, their place of employment and their average hourly wages. These tables include estimates only for residents 18 years or older. Estimates are provided for residents by type of operation of the facility (Table 33), ICF-MR status (Table 34), and facility size (Table 35).

**Works for pay.** An estimated 38.8% of persons with mental retardation and related conditions living in mental retardation facilities were employed for pay. Proportions of residents employed for pay ranged from 59.6% of residents of small facilities, including 74.4% of small, private nonprofit facility residents, to 30.2% of large facility residents, including 25.4% of large public facility residents. ICF-MR residents were much less likely to have paid work than residents of non-certified facilities (32.1% and 49.1%, respectively), although the proportion of small ICF-MR and small non-ICF-MR residents with paid employment was essentially the same (60.6% and 59.2%).

**Location of employment.** An estimated 26.3% of residents of mental retardation facilities worked for pay off the grounds of the residential facility in which they lived. This represented 67.8% of all employed residents. Major differences were noted among facility types in location of employment, with 92.6% of small facility paid workers being employed away from the facility as compared with 47.7% of paid workers living in large facilities.

ICF-MR residents with paid jobs were much less likely to have jobs away from the residence than were residents of noncertified facilities (50.8% and 85.1%, respectively). Not only were residents of institutions with 300 or more residents least likely to have a paid job (25.6%), but only an estimated 4% had a paid job away from the residential facility.

**Type of employment.** Sheltered workshops were the primary source of employment for residents of mental retardation facilities. An estimated 29.8% of mental retardation facility residents worked in sheltered workshops. This represented an estimated 76.8% of all residents working for pay. Although, as noted above, the different types of facility differed greatly in the proportion of their adult residents working in any type of setting for pay, the proportion of all workers who were employed in sheltered workshop settings was fairly consistent across facilities, with between 67% and 87% of employed residents employed by sheltered workshops. Only 3.0% of all residents (7.7% of employed residents) were in supported work programs, and even fewer (1.4%) were in competitive employment settings. Residents of small public facilities and nonprofit facilities of all sizes were most likely to be in supported or competitive employment (8.4% and 7.3%, respectively). Work for pay other than sheltered, supported or competitive employment, most frequently “in facility” work of various types, was reported for 4.8% of residents and was most common for private nonprofit facility residents (8.1%).

**Work with nonhandicapped people.** A very small proportion of residents of mental retardation facilities worked with persons who are not handicapped (7.1% of all residents and 18.3% of employed residents). A higher proportion of small facility residents worked with nonhandicapped persons than did large facility residents (10.9% and 5.6%, respectively). Only an estimated 18% of paid workers from both large and small facilities were employed in settings that also had nonhandicapped workers. Of all facility types, small ICFs-MR had the highest percentage of all residents (15.8%) and the highest proportion of employed residents (26.1%) in integrated employment settings.

**Hourly wages.** The estimated average hourly wage for paid workers living in mental retardation facilities was \$125 per hour. (Unfortunately NMES did not request information on total hours worked so as to permit estimations of total income from work.) Average wages varied relatively little by size of the residence in which people lived, with employed residents of small facilities averaging \$1.29 per hour and employed residents of large facilities averaging \$1.21 per hour. Considerable variability was noted in the average hourly wages of workers living in various types of facilities (from \$1.02 for public institution residents to \$1.48 for residents of large private facilities). ICF-MR residents with jobs averaged \$1.16 per hour as compared with an average of \$1.34 for residents of noncertified facilities. Of course, two of the major factors in the earnings of persons sampled are capacity for productivity and provision of opportunity to work for pay. These two factors did not appear to be equally distributed among the various types of residential facilities.

While there is not consistent association between wages and type of residence, there was a strong association between wages and type of employment. People in sheltered

work averaged \$1.02 per hour and had the lowest average pay of all types of workers in all sizes and types of facilities studied. Sheltered workshop wages averaged \$1.06 per hour in small facilities and \$.98 per hour in large facilities. People in nonsheltered work arrangements earned considerably more than the sheltered workshop employees, but because sheltered work was by far the most frequently used type of work (67.8% of workers), workshop wages were the primary factor in the low average wages of people with mental retardation and related conditions in mental retardation facilities. People involved in supported employment averaged \$2.15 per hour (\$2.21 in small facilities and \$2.09 in large facilities). Average wages in supported employment were between average wages received for sheltered employment and competitive employment for people living in all types and sizes of facilities. The average hourly wage for persons in competitive employment was \$3.87 per hour (\$3.77 for small facility residents and \$3.93 for large facility residents). In addition an average of \$1.35 per hour was derived from the "other" employment arrangements noted for about 4.8% of residents. Most of the persons with "other" paid jobs had "in facility" jobs.

**TABLE 33. Employment Status of Adult Residents of Mental Retardation Facilities by Facility Operation**

	Facility Operation									All Facilities		
	Private for Profit			Private Nonprofit			Public					
	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total	15-res.	16+ res.	Total
<b>Works for Pay</b>												
In facility	0.9	3.2	2.3	7.2	20.4	13.0	2.3	20.4	19.0	4.4	15.8	12.5
Away from facility	40.1	25.6	30.9	67.2	28.0	50.0	46.9	5.0	8.0	55.2	14.4	26.3
Total	41.0	28.8	33.2	74.4	48.4	63.0	49.2	25.4	27.0	59.6	30.2	38.8
<b>Type of Employment</b>												
Sheltered employment	35.6	22.9	27.5	60.3	32.4	47.8	40.3	18.3	19.9	49.3	21.8	29.8
Supported/transitional	2.8	1.0	1.6	4.4	4.6	4.6	8.4	2.5	3.0	4.3	2.5	3.0
Competitive employment	1.1	2.3	1.8	2.4	3.2	2.7	0.0	0.2	0.2	1.7	1.2	1.4
Other	1.7	2.9	2.4	7.7	8.3	8.1	0.6	4.4	4.2	4.8	4.9	4.8
Total	41.2	29.1	33.3	74.8	48.5	63.3	49.3	25.4	27.3	60.1	30.4	39.0
<b>Works with Non-handicapped People</b>	10.6	5.2	7.1	12.6	9.4	11.2	2.7	4.6	4.5	10.9	5.6	7.1
<b>Hourly Wages by Type</b>												
Sheltered employment	1.28	1.02	1.16	0.87	0.95	0.89	1.64	0.97	1.09	1.06	0.98	1.02
Supported/transitional	2.16	3.17	2.55	2.29	2.65	2.42	1.94	1.65	1.70	2.21	2.09	2.15
Competitive employment	2.43	3.43	3.13	4.32	4.27	4.27	–	5.00	5.00	3.77	3.93	3.87
Other	1.86	0.81	1.08	1.86	1.81	1.81	–	0.71	0.71	1.86	1.12	1.35
Average hourly wage	1.37	1.19	1.33	1.17	1.26	1.26	1.69	1.02	1.13	1.29	1.21	1.25
<p><u>Notes.</u> Table includes only residents age 18 or older. Total by "Type of Employment" may not equal total "Works for Pay" because of varying item response rates. A "–" denotes missing data.</p>												

**TABLE 34. Employment Status of Adult Residents of Mental Retardation Facilities by ICF-MR Certification Status**

	ICF-MR Certification Status						All Facilities		
	ICF-MR Certified			Not Certified			15- res.	16+ res.	Total
	15- res.	16+ res.	Total	15- res.	16+ res.	Total			
<b>Works for Pay</b>									
In facility	8.0	17.2	15.8	2.7	12.1	7.3	4.4	15.8	12.5
Away from facility	52.6	9.7	16.3	56.5	26.8	41.8	55.2	14.4	26.3
Total	60.6	26.9	23.1	59.2	38.9	49.1	59.6	30.2	38.9
<b>Type of Employment</b>									
Sheltered employment	47.9	19.9	24.2	50.0	26.7	38.6	49.3	21.8	29.8
Supported/transitional	5.8	2.1	2.6	3.5	3.6	3.6	4.3	2.5	3.0
Competitive employment	1.6	0.6	0.8	1.7	2.9	2.3	1.7	1.2	1.4
Other	5.5	4.5	4.7	4.4	5.8	5.1	4.8	4.9	4.8
Total	60.8	27.1	32.3	59.6	39.0	49.6	60.1	30.4	38.9
<b>Works with Non-handicapped People</b>	15.8	4.6	6.3	8.6	8.1	8.4	10.9	5.6	7.1
<b>Hourly Wages by Type</b>									
Sheltered employment	1.12	0.97	1.03	1.03	0.99	1.01	1.06	0.98	1.02
Supported/transitional	1.96	1.70	1.80	2.46	2.84	2.63	2.21	2.09	2.15
Competitive employment	3.64	5.31	4.67	3.82	3.32	3.52	3.77	3.93	3.87
Other	2.45	0.53	0.90	1.53	2.30	1.94	1.86	1.12	1.35
Average hourly wage	1.62	1.05	1.16	1.23	1.53	1.34	1.29	1.21	1.25
<b>Notes.</b> Table includes only residents age 18 or older. Total by "Type of Employment" may not equal total "Works for Pay" because of varying item response rates.									

<b>TABLE 35. Employment Status of Adult Residents of Mental Retardation Facilities by Facility Size</b>							
	<b>Number of Residents in Facility</b>						<b>Total</b>
	<b>1-6 res.</b>	<b>7-15 res.</b>	<b>16-75 res.</b>	<b>76-299 res.</b>	<b>300-799 res.</b>	<b>800+ res.</b>	
<b>Works for Pay</b>							
In facility	4.4	4.3	6.7	15.8	20.8	25.8	12.5
Away from facility	48.0	60.4	30.2	14.4	3.8	2.9	26.3
Total	52.4	64.7	36.9	30.2	24.6	28.7	38.8
<b>Type of Employment</b>							
Sheltered employment	44.8	52.5	27.1	21.1	19.6	15.2	29.8
Supported/transitional	3.0	5.2	2.1	3.1	2.2	2.9	3.0
Competitive employment	1.7	1.6	2.5	1.3	0.3	0.6	1.4
Other	3.6	5.6	5.3	5.1	2.7	9.9	4.8
Total	53.1	64.9	37.0	30.6	24.8	28.6	39.0
<b>Works with Non-handicapped People</b>	6.3	14.1	6.2	6.4	3.4	8.7	7.1
<b>Hourly Wages by Type</b>							
Sheltered employment	1.19	0.99	1.18	0.84	0.78	0.99	1.02
Supported/transitional	2.18	2.23	2.63	2.17	2.48	1.67	2.15
Competitive employment	2.89	4.39	3.27	5.43	3.00	5.00	3.87
Other	3.75	1.18	1.70	0.77	1.01	0.59	1.35
Average hourly wage	1.47	1.19	1.48	1.16	0.96	1.01	1.25
<u>Notes.</u> Tables includes only residents age 18 or older. Total by type of employment may not equal total employed because of varying item response rates.							

## **Characteristics by Level of Mental Retardation**

Table 36 presents estimates of selected characteristics of residents with mental retardation and related conditions in mental retardation facilities by their reported level of retardation or for those residents reported to have “related conditions” only.

### **Activities of Daily Living**

Statistics on independent performance of selected activities of daily living showed clear and expected associations with level of mental retardation. Among persons with borderline/mild, moderate and severe mental retardation there were progressive

decreases in the proportion of residents reported to be independent in performance of activities of daily living as the reported severity of cognitive impairment increased. But among people with profound mental retardation, there was much less independence reported in key activities of daily living than among people with severe mental retardation. With respect to the proportion independently performing key activities of daily living, persons with related conditions only (i.e., reported not to be mentally retarded) tended as a group to have reported levels of independence which averaged in the range between people with moderate and people with severe mental retardation. However, it should be noted that this group represented only about 1% of the sample (33 sample members) and these estimates have limited reliability.

There was a notable magnitude of the difference between residents with mild/borderline mental retardation and profound mental retardation in ability to perform basic self-care tasks independently. An estimated 79.5% of the former, but only 6.5% of the latter were reported to be able to bathe independently; 85% of the former, but only 9% of the latter were reported to be able to dress themselves independently. Clearly the strong association between the residents' degree of mental retardation and their abilities to perform activities of daily living independently was a primary factor in the differences among facilities in residents' levels of independence (see Tables 18-23).

### **Use of Special Equipment**

Of the estimated 19.0% of residents of mental retardation facilities using wheelchairs, most, were profoundly retarded. The 39.1% of persons with profound mental retardation living in mental retardation facilities made up 75.6% of all mental retardation facility residents using wheelchairs. Very small proportions of residents required catheterization (.9%), with no appreciable difference by level of retardation. Very small proportions of residents used symbol systems or communication boards as their usual means of communication (1.1%). The estimated percentage of sample members with related conditions but not mental retardation using such devices (3.6%) was slightly higher than the percentage for persons with mental retardation, but this difference was not statistically significant.

### **Special Conditions**

**Epilepsy.** An estimated 29.9% of persons with mental retardation and related conditions in mental retardation facilities were reported to have epilepsy. The prevalence of epilepsy was strongly associated with residents' level of retardation, occurring in an estimated 15.5% of residents with mild/borderline mental retardation, 21.5% of persons with moderate mental retardation, 26.7% of persons with moderate mental retardation, and 43.2% of persons with profound mental retardation. About two-thirds (67.0%) of the small number of mental retardation facility residents with related conditions only (i.e., not mental retardation) had epilepsy.

**Cerebral palsy.** An estimated 11.9% of persons with mental retardation and related conditions in mental retardation facilities were reported to have cerebral palsy. The prevalence of cerebral palsy was also substantially related with level of mental retardation, being reported for only 6.0% of residents with mild or moderate mental retardation, but 9.3% of residents with severe mental retardation and 19.5% of residents with profound mental retardation. About a quarter (25.6%) of the residents who were reported to have related conditions only had cerebral palsy.

**Autism.** An estimated 3.6% of the people with mental retardation and related conditions living in mental retardation facilities were indicated to have autism recorded in their medical records. This condition was most commonly recorded for persons with related conditions but not mental retardation (10.6%) and persons who were reported to be severely mentally retarded (5.7%). The lack of a higher recorded prevalence of “autism” among persons with profound mental retardation may derive from respondents attributing certain autistic-like behavior among persons with profound mental retardation (e.g., self-stimulation or detachment from other people) to the individual's profound mental retardation rather than to the condition of “autism” per se.

**Blindness.** An estimated 4.4% of persons with mental retardation and related conditions in mental retardation facilities were totally blind. Although relatively rare overall, blindness was associated with the level of mental retardation recorded in the medical records of sample members. While only 1.1% of persons with mild or moderate mental retardation and 2.5% of persons with severe mental retardation were reported to be blind, 9.5% of persons with profound mental retardation were reported to be blind.

**Deafness.** Only an estimated 1.7% of residents of mental retardation facilities were reported to be completely deaf. Deafness was not associated with level of mental retardation.

**Circulatory conditions.** An estimated 10.8% of residents of mental retardation facilities have circulatory system conditions. There is a small association of these conditions with the less severe levels of mental retardation. This relates to the strong association between circulatory system conditions and older age, and the lower proportions of persons with profound mental retardation among older residents.

## **Problem Behavior**

**Hurting others.** An estimated 30.3% of mental retardation facility residents were reported to on occasion attempt to hurt other people. The prevalence of aggressive behavior was highest among persons with severe mental retardation (40.6%), with fairly consistent rates (between 24.7% and 30.6%) reported for other groups.

**Hurting self.** An estimated 24.4% of persons with mental retardation and related conditions living in mental retardation facilities were reported to on occasion hurt themselves physically. Reported prevalence was highest among persons with severe and

profound mental retardation (29.4% and 29.8%, respectively) and lowest among persons with mild/borderline mental retardation and people who had related conditions but were not mentally retarded (13.0% and 11.0%, respectively).

<b>TABLE 36. Selected Characteristics and Service Use of Persons in Mental Retardation Facilities by Level of Mental Retardation</b>						
	<b>Level of Mental Retardation</b>					
	<b>Borderline/ Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Profound</b>	<b>Related Condition</b>	<b>All Residents</b>
<b>Activities of Daily Living</b>						
% Bathes independently	79.5	58.5	33.6	6.5	47.7	38.5
% Dresses independently	85.0	68.3	44.5	9.2	58.3	45.0
% Uses toilet independently	94.0	88.9	76.6	32.2	78.1	66.5
<b>Special Equipment/Devices</b>						
% Uses wheelchair	4.5	5.5	11.3	39.1	16.2	19.0
% Uses urinary catheter	1.0	0.4	0.8	1.3	0.0	0.9
% Uses symbol system/ communication board	0.5	0.5	1.5	1.6	3.6	1.1
<b>Special Conditions</b>						
% Epilepsy	15.5	21.5	26.7	43.2	67.0	29.9
% Cerebral palsy	5.6	6.4	9.3	19.5	25.6	11.9
% Autism	1.5	3.4	5.7	3.6	10.6	3.6
% Blind	0.8	1.4	2.5	9.5	0.0	4.4
% Deaf	1.4	1.2	1.8	2.0	3.2	1.7
% Circulatory system conditions	13.2	13.6	11.8	7.0	20.2	10.8
% Frequent constipation	10.1	11.7	15.5	36.3	16.1	21.3
<b>Problem Behavior</b>						
% Hurts others physically	24.7	30.6	40.6	27.9	22.9	30.3
% Hurts self physically	13.0	22.1	29.4	29.8	11.0	24.4

## **PART 3: ALTERNATIVE POPULATION ESTIMATION**

### **Overview**

Part I of this report noted a number of significant limitations in the sample frame for the Institutional Population Component of NMES. It was noted that there is strong evidence that this caused substantial underrepresentation of smaller community-based residential facilities and their residents in the National Medical Expenditure Survey. The general direction of underrepresentation of small facility residents is clear: "facilities" with 1 or 2 residents were completely eliminated from the study when it became apparent that the sample frame contained only a small proportion of all such facilities nationwide, and there was also considerable underrepresentation of other small facilities.

Corroboration regarding underestimation of small facilities and their residents comes from state reports on the number of facilities that they have under licensure or contract or that they directly operate, and the number of people with mental retardation and related conditions living in them (Lakin, et al., 1989). In addition, the estimation from NMES that the number of small community facilities and residents in 1987 was essentially unchanged from the 1982 NCRF (Lakin, Hill, & Bruininks, 1985), while state institution populations decreased by 25,000 people (most of whom were released into community-based group settings) seems implausible and also suggests underrepresentation of small facilities in the NMES population estimates. As noted earlier, estimates of persons in large facilities were reasonably comparable to expected values.

Given the problems with the estimates in the Institutional Population Component, consideration of ways to adjust this data source to permit more accurate population estimates seems warranted. In the following pages the simplest available method of compensating for the underrepresentation of small facilities is explored. However, it is important to note at the outset that data to assess the precision of any alternative estimates are not available.

### **An Alternative Estimation Procedure**

The simplest alternative procedure for using the Institutional Population Component statistics to obtain more realistic estimates of the populations of residential facilities for people with mental retardation, particularly the smaller ones, is to in effect reweight its sample to reflect known populations of different types of facilities. This can be done by using the proportional estimates from the 1987 NMES sample, those reported in Part 2 and applying them to more accurate total population statistics on people in mental retardation facilities by size and type as are known and reported by the individual states. Such statistics, based on June 30, 1987 reports of all state mental retardation/developmental disabilities agencies, are available (Lakin et al., 1989). These

statistics generally coincide with the dates of the NMES interviews. These statistics indicate that small (15 or fewer resident) mental retardation facilities did not house 65,000 people in 1987, they housed on the order of 118,500 people. Use of the data obtained in NMES to respond to the practical questions asked about mental retardation facilities and their residents in most instances need to reflect that reality.

Table 37 presents selected characteristics of the NMES sample which have been adjusted to the nationally aggregated reports of individual states regarding the populations of people with mental retardation and related conditions in mental retardation facilities in June 30, 1987. In Table 37, the statistics presented outside of parentheses are the proportions of all residents within facility categories reported to exhibit the selected behaviors/conditions as obtained from the analyses reported in Part 2. In parentheses are population estimates obtained when these proportions were applied to national population statistics reported by the states.

These alternative population estimates are briefly discussed in the following pages. These comments focus primarily on the differences of significance between the estimated populations of small mental retardation facilities, which the Institutional Population Component estimated to be 64,936 people with mental retardation and related conditions in 1987, but which states reported to be 118,570 people on June 30 of that same year. Following this presentation is a discussion of the extent to which evidence exists to support such alternative estimates.

### **Level of Mental Retardation**

According to the NMES population estimates, in 1987 there were an estimated 8,834 people with profound mental retardation in small mental retardation facilities. This represented 13.6% of the population estimated to be in small facilities (64,939). If the 13.6% of all residents were applied to the state reported population of facilities with 15 or fewer residents, an estimated small facility population of 16,126 persons with profound mental retardation would be obtained. Similarly, the NMES estimated 15,258 persons with severe mental retardation in the smaller community based facilities. Application of NMES proportional estimates to the known population of the smaller facilities would yield an estimate of 27,864 people with severe mental retardation in community facilities.

Adjusting the NMES statistics may have importance beyond that of improved accuracy of estimate. Considerable debate continues at the federal and state levels with respect to the continuing need for institutional care. Many questions raised in this debate revolve around whether appropriate services can be provided for people with the most severe handicaps with small community settings. Clearly the extent to which community-based living is already being provided to persons with severe impairments is important evidence of the viability of community living settings for all, or virtually all, persons with mental retardation and related conditions. Regarding this issue an estimate that 16,126 persons with profound mental retardation (or 20% of persons with profound mental retardation in mental retardation facilities) are currently living in community facilities

suggests significantly different placement practices and community residential services viability than an estimate of 8,834 (or 12% of persons with profound mental retardation in mental retardation facilities).

<b>TABLE 37. Characteristics of People in Different Facility Types<sup>1</sup></b>			
	<b>Small 15- Res (118,570)</b>	<b>Large</b>	
		<b>Large Public (95,052)</b>	<b>All Large (137,113)</b>
<b>Level of Mental Retardation</b>			
Profound	13.6% (16,126)	59.5% (56,556)	46.3% (63,493)
Severe	23.5% (27,864)	20.2% (19,200)	19.2% (26,330)
<b>Disturbing Behavior</b>			
Tries to hurt other	25.2% (29,880)	33.6% (31,937)	29.9% (41,003)
Tries to hurt self	19.4% (23,003)	23.6% (22,432)	28.4% (38,946)
Steals from others	15.0% (17,786)	17.2% (16,349)	16.0% (21,941)
Exposes self/has problem sexual behavior	12.1% (15,058)	14.5% (13,783)	12.4% (17,004)
Gets lost/wanders	12.7% (15,058)	16.8% (15,969)	15.1% (20,707)
Unable to avoid dangerous things/places	18.9% (22,410)	31.8% (20,227)	25.6% (35,106)
Cries for long periods for no apparent reason	12.9% (15,296)	12.4% (11,786)	12.3% (16,876)
Gets upset/yells	49.6% (58,811)	54.5% (51,803)	51.6% (70,761)
<b>Functional Skills</b>			
Dresses with no difficulty/without help	62.6% (74,225)	27.3% (25,949)	38.4% (52,659)
Uses toilet with no difficulty/without help	86.0% (101,970)	51.7% (49,142)	60.4% (82,828)
Walks across room with no difficulty/without help	91.2% (108,136)	66.0% (62,734)	71.4% (97,913)
<b>Special Equipment</b>			
Wheelchair	5.0% (5,929)	29.8% (28,325)	23.1% (31,678)

	Small 15- Res (118,570)	Large	
		Large Public (95,052)	All Large (137,113)
Urinary Catheter	0.5% (593)	1.1% (1,046)	1.2% (1,646)
Communication board/symbols system	0.4% (474)	1.2% (1,141)	1.3% (1,783)
<b>Medical Conditions</b>			
Comatose <sup>2</sup>	—	—	—
Circulatory conditions	12.2% (14,466)	9.9% (9,410)	10.3% (14,125)
Diabetes	2.0% (2,371)	1.6% (1,521)	2.0% (2,743)
Frequent constipation	11.5% (13,636)	31.3% (29,751)	24.8% (34,009)
Deaths	0.9% (1,067)	1.4% (1,331)	1.6% (2,194)
<b>Notes.</b>			
1. Data presented are from the 1987 National Medical Expenditure Survey (NMES) of the National Center on Health Services Research, U.S. Public Health Service. Numbers presented are proportions of all residents in each type of facility with the characteristic noted. Numbers in parentheses are estimated total number of persons with the characteristics nationwide, based on NMES proportions of residents by facility category and state reports of total residents in each category.			
2. None of the 3,618 sample members had this condition.			

### **Disturbing Behavior**

Estimated proportions of residents with mental retardation and related conditions exhibiting on occasion various types of disturbing behavior indicates the general prevalence of such behavior to be relatively similar in large and small facilities (again, with the important caveat that the Institutional Population Component did not include data on frequency, duration or intensity of these types of behavior). Simple reweighting of the NMES proportions to the known populations of small and large facilities increases population estimates of persons with behavior problems in small facilities by 82.6%. Again, the adjustments have the effect of suggesting that community-based settings are currently providing residential services to many more thousands of people with problem behavior than would be suggested by the original NMES estimates.

### **Functional Skills**

Proportions of persons with mental retardation and related conditions in small and large mental retardation facilities show small facility residents to much more often relatively independent in functioning. However, if proportional statistics are adjusted to known

populations, it is notable that there are as many people estimated to be able to dress without assistance in large facilities as in the smaller community-based facilities. There are nearly as many people able to use the toilet independently in large facilities as in smaller community-based facilities (81% of the small facility estimate) and there are nearly as many people able to walk across the room independently in the large facilities as in the small facilities (91% of the small facility estimate). Without adjustments to known populations, estimates from NMES would suggest a much greater proportion of people with significant functional limitations living in large facilities than is actually the case. For example with respect to independent toilet use, NMES population estimates indicate that 86.9% of all residents of mental retardation facilities cannot independently use the toilet live in large facilities. Use of alternative population statistics produces an estimate of 76.4% of all residents not independent in toilet use are living in large facilities. As a result, not being able to independently toilet oneself appears less accepted (and perhaps less acceptable) as a criterion for limiting community living opportunities.

### **Use of Special Equipment**

Wheelchair use is considerably more prevalent in large facilities than in small facilities. Adjusting the NMES estimates to reflect the considerably greater number of persons of smaller community facilities and the somewhat smaller number of persons in larger facilities than estimated in NMES would nearly double the estimated wheelchair users in smaller facilities from an estimated 3,237 persons to an estimated 5,929 persons. Reported use of urinary catheters and communication boards/symbol systems as primary means of communication was so limited in the NMES sample that it was affected by reweighting.

### **Medical Conditions**

Applying proportional estimates from NMES to the known populations of facilities as reported by the states has various effects on estimates of medical conditions. For circulatory conditions, reweighting would provide an estimate that slightly more people with mental retardation and related conditions and circulatory system conditions are living in smaller, community based residential facilities than in larger facilities, while in the original NMES estimates only 33.3% of residents with circulatory conditions are indicated to live in the smaller facilities. With proportional adjustments the estimated numbers of people with diabetes in small mental retardation facilities increased by 2,250 (or 82%), or an estimated 46.4% of all mental retardation facility residents with diabetes living in community-based settings (an increase from 29.9% in the original NMES estimates). Reweighting of the NMES sample also makes considerable difference in estimated proportion of residents with frequent constipation living in community settings. In the original NMES estimates, 16.4% of all residents in mental retardation facilities who suffered frequent constipation were in small facilities with reweighting that proportion would be 28.6%.

The proportion of deaths among smaller, community-based facility residents was estimated to be .9%. This was similar to the .8% death rates obtained for small facility residents in the 1977 and 1982 NCRF surveys (Lakin, Hill, & Bruininks, 1985). But the total number of deaths among residents in the smaller residential facilities is probably better estimated by reweighting the NMES sample to known number of residents. The adjusted estimate would be 1,067 deaths in smaller, community facilities as compared with the original NMES estimate of 615 deaths in these facilities.

## **Justification of the Alternative Procedure**

There are at least three conditions that would have to prevail to make this or any similar alternative estimation procedure adequate and preferable to using original NMES statistics for estimating persons with mental retardation and related conditions in different sizes and types of residential facilities. These include the following:

- *States must more accurately report the total number of people making up the populations of facilities meeting the definitions employed in NMES than did the ILTCP, which served as the sample frame for NMES and is the basis for its population estimates.* Based on the discussion in Part I of this report, this does appear to be the case.
- *The sample size of NMES must be sufficient to yield accurate estimates of facility and population characteristics for settings with 15 or fewer residents.* The NMES sample of 326 facilities and over 1,000 residents in facilities with 3-15 “beds” appears more than sufficient to obtain reasonably accurate estimates of the proportional distributions reported for these facilities. Although, for certain data elements, the relatively low occurrence within the sample produced estimates of low reliability, in general relatively adequate sample size was maintained among the smaller facilities.
- *Sample members representing the approximately 65,000 community facility residents in the facilities contained in the sample frame must also be reasonably representative of those who were excluded from the sample frame and, thereby, the sample (both 1 and 2 resident places and the facility “types” underrepresented).* It is extremely difficult to test whether this condition can be met satisfactorily. In general the residents of small facilities sampled in the 1987 NMES tend to be somewhat more impaired than residents of facilities participating in the 1982 NCRF. As such the NMES estimates of small community facility population characteristics tend to reflect what is known to have taken place within residential services nationwide since the 1982 NCRF. Since 1982 smaller facilities are known to have come to serve considerably more severely impaired people, as thousands of persons with severe and profound levels of mental retardation were released from public and private institutions to community facilities or have entered community facilities directly from

their own homes. Table 38 compares estimated populations and proportions by level of mental retardation in the 1982 NCRF and the 1987 NMES, original and adjusted estimates.

<b>TABLE 38. Comparison of 1982 NCRF and 1987 NMES Findings Regarding Small Facility Populations with Mental Retardation</b>					
	<b>Small Facility Populations</b>	<b>% Mild/ Borderline</b>	<b>% Moderate</b>	<b>% Severe</b>	<b>% Profound</b>
<b>1982 NCRF</b>	(proportion) 63,703	(29.3%) 18,665	(37.4%) 23,825	(23.5%) 14,970	(9.7%) 6,179
<b>1987 NMES</b>	(proportion)	(30.9%)	(31.7%)	(23.7%)	(13.7%)
Original estimate	64,338*	19,880	20,395	21,810	8,750
Adjusted estimate	118,570	36,638	37,587	28,101	16,244

\* Excludes 598 estimated people with related conditions but not mental retardation.

The estimated proportional changes in small facility residents by level of mental retardation suggested are generally supported by census statistics gathered on the populations of state institutions. Between June 30, 1982 and 1987 state mental retardation institution populations decreased from 121,479 to 94,696 (White et al., 1989). During that period states reported a total of 43,189 discharges from state institutions. Based on the only available statistics on the placement of state institution discharges for FY 1982, FY 1985 and FY 1987 (the only years in which data were gathered), 50.67% of discharges went to community-based living arrangements other than a natural or adoptive home. In other words, an estimated 21,880 people were discharged to state institutions to community living arrangements between June 30, 1982 and June 30, 1987. If data on the level of mental retardation of FY 1987 releases (the only year available) are applied to these data, the estimated number and proportions of persons with different level of mental retardation entering community facilities would be as shown in Table 39.

Of course, not all releases to community facilities have resulted in successful tenure. In the only two years during the 1982-1987 period in which data were obtained on readmissions, FY 1985 and FY 1987, 33.9% and 32.5% of readmissions, respectively, were from people living in community facilities other than a natural or adoptive home. Adjusting data on total readmissions for FY 1982, 1985 and 1987 with the statistics on readmissions from community settings, and using data on the level of retardation of readmissions from FY 1987 (the only year available), the estimated number and proportion of persons with different levels of retardation leaving community facilities to return to institutions would be as shown in Table 39.

**TABLE 39. Estimated Additions to Community Facilities from State Institutions during the period from 1982 to 1987 by Level of Mental Retardation**

Change	Estimated Gain/Loss	Level of Mental Retardation			
		Mild/ Borderline	Moderate	Severe	Profound
Moves from State Institution to Community	+21,880	+3,960 (18.1%)	4,770 (21.8%)	5,973 (27.3%)	7,177 (32.8%)
Moves from Community to State Institution	-3,420	-752 (22.0%)	-759 (22.2%)	-814 (23.8%)	-1,095 (32.0%)
Net Change	+18,460	3,208 (17.3%)	4,011 (21.7%)	5,159 (27.9%)	6,082 (32.9%)

Of course, a limitation of these data is that they assume that people with more severe mental retardation released from institutions are as likely to be among the 51% going to community facilities as are released residents with less severe levels of mental retardation. Put another way, one might question whether it is possible that people with severe or profound mental retardation would be more likely to be among the 49% of institution discharges who did not go to community residential facilities. Unfortunately, the most recent data on this topic (1978) are too dated for contemporary analysis. However, among the estimated 14% of all institution discharges returning to a natural or adoptive home in 1978, no statistically significant differences were noted by degree of mental retardation. While available statistics do not prove absolutely that the populations of community mental retardation facilities have necessarily changed in the absolute size and distribution as suggested by related movement statistics, it seems reasonable to estimate that the depopulation of state institutions alone has added over 18,000 people to community residential settings between 1982 and 1987, an estimated 6,000 of whom are profoundly retarded.

As important as these additions are to the number and characteristics of residents of community mental retardation facilities, persons coming from large public institutions comprise a significant minority of persons entering smaller residential facilities. In the 1982 NCRF statistics were gathered on previous place of residence of persons newly admitted between July 1, 1981 and June 30, 1982 to 88% of all facilities operating on June 30, 1982. These statistics showed an estimated 13,030 new admissions to smaller community facilities in FY 1982, 27% came from large public facilities. Another 8% came from large private mental retardation facilities and 6% from other types of institutions (nursing homes, mental health facilities, hospitals, etc.). About 28% of new residents came directly from home or independent living situations and 31% came from other community facilities or moved to a new home with their existing residential household (Lakin, Hill, & Bruininks, 1985). Unfortunately no data exist on the characteristics of these new admissions. In addition statistics reported by states on the number of people in large nonstate residential facilities indicated a decrease of above 10,600 residents between June 30, 1982 and June 30, 1987 (Lakin et al., 1989). Presumably most of this number was made up of persons moving to community facilities.

Clearly the group most systematically underrepresented in the mental retardation facilities sample are persons in family/foster care settings. With an average size of 2.6 residents per “facility” (Lakin, Hill, & Bruininks, 1985), the majority of such facilities were automatically excluded from NMES when it was decided to exclude facilities of 1 and 2 residents. A large (unknown) proportion of the others were left unidentified because of the factors discussed in Part I. Given the exclusion of most foster care facilities which served an estimated 22,353 people on June 30, 1987, there is particular interest regarding the extent to which their residents might be represented in data gathered in NMES. Statistics obtained on the 17,147 residents of foster care facilities in 1982 showed that with respect to level of mental retardation foster care residents were quite similar to residents of other small facilities as shown in Table 40. While minor differences are apparent in the level of retardation of specialized foster care and other small facility residents in 1982, these differences were not large. However, age differences were substantial. While 37.4% of foster care residents were 21 years or younger, only 18.0% of other small facility residents were 21 years and younger. Therefore, with respect to NMES statistics, it seems clear that the exclusion of foster care homes of 1 and 2 residents and underrepresentation of the remainder has caused significant underrepresentation of children and youth in the sample and resulting population estimates. This underestimation appears to be about 3% of all residents, about 6,000-8,000 persons 21 years or younger, or an estimated 12%-16% of the expected number of persons of that age.

**TABLE 40. Comparison of 1982 Foster Care Residents with Small Facility Resident Characteristics as Obtained in the 1982 NCRF and 1987 NMES**

	<b>% Mild/Borderline</b>	<b>% Moderate</b>	<b>% Severe</b>	<b>% Profound</b>
1982 Foster Care (NCRF)	25.9%	37.7%	26.0%	10.4%
1982 All Other Small (NCRF)	30.4%	37.3%	22.7%	9.6%
1987 Small (NMES Est.)	30.9%	31.7%	23.7%	13.7%

In summary, there is no way to clearly demonstrate how best to use the NMES statistics to estimate populations of persons with mental retardation and related conditions in mental retardation facilities, especially the smaller facilities. While there is overwhelming evidence that NMES has substantially underrepresented the populations of persons in small facilities, it remains the richest and most comprehensive data base on residential services for persons with mental retardation available. There is much evidence that the general characteristics of small community facility populations are shifting proportionally in the directions suggested by NMES. Unfortunately data do not exist to clearly guide adjusting NMES estimates to known total small facility populations so as to improve the ability to estimate the characteristics of the population. Nevertheless, some “reweighting” is inevitable in the many instances where population estimates needed and where NMES represents the single best data source of estimating the characteristics of residents, costs of residential services, and other data needed about mental retardation facilities. Simple efforts to do so will probably improve the ability of the NMES statistics to describe the population characteristics and residential services of persons living in small,

community based residential settings. However, data to establish or justify specific procedures for doing so are not readily available.

## **PART 4: SUMMARY AND CONCLUSIONS**

This report has described the basic design, study limitations and initial findings from the 691 mental retardation facilities and 3,618 of their residents sampled in the Institutional Population Component of the National Medical Expenditure Survey. General aspects of the design and limitations of this study were described primarily in Part 1. Part 2 and Part 3 presented the basic statistics gathered in the study. The few concluding comments made here summarize some of the more important observations and implications regarding the design and key findings of the study.

### **Study Design**

The sample size and broad coverage of mental retardation facilities and residents in the Institutional Population Component of NMES will yield much information of value regarding the residential living arrangements of persons with mental retardation and related conditions. At the same time the study's sample frame limitations, and thereby its sample limitations, demonstrate the importance of assuring that any sample survey of persons in residential settings begins with the most comprehensive "universe" of facilities feasible. It is axiomatic, but certainly not trite, to observe that a sample can be no better than the sample frame. There is no way in the latter stages of a sample survey to compensate for inadequate efforts to understand and identify the universe of facilities being studied. Based on work with the NMES sample frame (the Inventory of Long-Term Care Places) as well as with the sample data themselves, the following general observations seem important lessons to derive from this study to guide other future studies of a similar nature.

1. *Sample frame construction must begin at the state level and permit tailoring to the idiosyncracies of each state.*

States differ in the components and organization of their service systems. A specific survey of each state to understand the different out-of-home services offered to persons with mental retardation and related conditions and to identify the individuals/agencies that can describe the necessary methods and key contacts for identifying and surveying all the settings within the services system is an essential first step to sample frame development. In states with decentralized service systems, often the only alternative to working with multiple state agencies and/or regional or county agencies is to accept an incomplete identification of facilities.

2. *Inclusion of some types of community-based residences in certain states will sometimes require the direct involvement of state agencies in the research.*

States are often reluctant to and/or directly prohibited from providing listings of their smallest residential settings, particularly those of a foster care model. To include such residential options in a national survey may require specific recruitment of the agencies controlling access to such facilities. For example in the 1982 University of Minnesota census survey of residential facilities for persons with mental retardation, New York State's Office of Mental Retardation/Developmental Disabilities directly distributed over 1,000 surveys to family care homes; Delaware distributed, collected and forwarded questionnaires from its 71 special foster care settings. The ILTCP did not utilize such a strategy, which probably contributed to the undercounting of small facilities. For example in New York the ILTCP included a total of 1,484 mental retardation facilities, which was 911 (or 38%) fewer than surveyed in the 1982 University of Minnesota study. In Delaware the 1986 ILTCP counted 22 facilities, which was barely a quarter of the 80 surveyed in 1982.

3. *The inclusion of residential options must be as comprehensive as feasible.*

In recent years there has been increasing attention to the thousands of facilities generically referred to as "board and care homes." Board and care is a generic term which generally is taken to mean out-of-home, community-based living arrangements which are not Medicaid certified and/or do not provide medical services, but which do provide care, protective oversight and often training to people living in them. These operate under a range of different labels in different states, (e.g., adult foster care, domiciliary care, group homes, semi-independent living arrangements). Such places are becoming more common as services become more community oriented, and as states try to respond to increasing demands for community services with limited funds. The movement away from the majority of residents being in one or two models of care, state institutions and/or ICFs-MR, has led to much greater complexity and variety in residential services. Study designs must attend to the importance of procedures that assure systematic and comprehensive inclusion of all forms of residential settings.

4. *Data on residents' service utilization and need, experiences and functional and behavioral characteristics are at least as important as population estimates.*

One of the strengths of NMES was its gathering of data on a large sample of persons in a wide range of residential settings (i.e., mental retardation, nursing and related care homes). However, it is important to assure not only that data collection include sufficient samples of individuals and settings, but also that the data collected respond directly to the contemporary issues in providing services. Despite NMES' being the largest ever study of individuals with mental retardation and related conditions in all types of residential settings, it did not directly respond to data needs in areas such as functional and dysfunctional behavior of residents, specific services provided and needed, daily living experiences and relationships, community participation and resource use, and other topics which are

important to understanding the current status and changing patterns of residential and related services.

5. *Careful attention must be given to the quality of instrumentation, especially in creating unambiguous, objective and quantifiable questions regarding important characteristics and experiences of persons with mental retardation and related conditions.*

In a number of areas the NMES attended to important topics, but did so in general and sometimes ambiguous ways that were often much less useful than they might have been. In many instances the specificity in the instrumentation was consistent with other federal health related surveys, but was considerably less than is typically used and generally expected in studies of persons with mental retardation and related conditions. For example, in the important area of challenging behavior, which is very frequently a critical characteristic, NMES asked, "Does (subject) sometimes disturb you or anyone else by [a list of potentially disturbing behaviors]?" These questions were presented with no severity or frequency indicators, making the intensity of the problem behavior impossible to assess. Examples of question terminology used in NMES that might have been ambiguous to respondents when applied to subjects with mental retardation are whether respondents "socialize" with friends or attend "meetings." Whether the interactions of persons with severe cognitive impairments would be interpreted as "socializing" or whether the group situations in which they find themselves would be seen as "meetings" is left to the interpretation of the respondent in many areas throughout the study, specific behaviorally defined items would have greatly improved the clarity of questions asked and data obtained.

6. *The operational definition of "residential facility" used in NMES and in previous national studies needs to be expanded.*

In the NMES, as in previous census studies which served to identify facilities for it, a "facility for the mentally retarded" was defined as:

- (1) A place or unit certified as an intermediate Care Facility for the Mentally Retarded (ICF-MR) by Medicaid.
- (2) A place or unit that is formally state-licensed, or contracted living quarters (a) with three or more beds for clients who reside there, (b) providing to mentally retarded persons either personal care (ADL or IADL) or protective oversight, i.e., 24 hour-a-day, seven-day-a-week supervision, (c) not a licensed hospital unless a hospital for the mentally retarded, and (d) not a family providing services exclusively to relatives. In the case of an MR unit within a hospital, only the MR unit of the hospital is eligible.

Increasingly the service providers for persons with developmental disabilities are attempting to provide the residential supports needed by individuals rather than exclusively focusing on the development of supervised congregate care settings. As this important

shift is taking place increasing numbers of people with developmental disabilities can be expected to be living in places that provide less than full-time protective oversight within the living unit. Such an orientation is supported by professional attitudes and program philosophies, as well as by federal policies such as Medicaid Home and Community Based Services.

7. *NMES shows the benefits of simultaneous gathering of identical data sets on persons in mental retardation facilities, as well as other nursing and related care facilities.*

A true strength of the NMES Institutional Population Component is that it included persons in mental retardation facilities and in nursing and related care homes and gathered comparable data on persons with mental retardation and related conditions in both classes of facility. The importance of this was further supported by the very small number of people (1%) identified as having related conditions, but not mental retardation who were living in mental retardation facilities. Quite apparently a national survey of persons with developmental disabilities in residential settings must include attention to facilities outside the traditional mental retardation programs.

## **Findings**

The limitations noted above notwithstanding, the NMES Institutional Population Component, including these initial data, as well as the service utilization, costs, resident movement and other data yet to be released, is an important data base for understanding the characteristics, needs and services of persons with mental retardation and related conditions in long-term care settings. In the following paragraphs a few of the more notable findings from these initial NMES data analyses are highlighted.

1. *Access to community living opportunities is growing for persons with all types and degrees of mental retardation and related conditions.*

One of the most striking findings from this study was the rapid increase in the number of persons with severe and profound mental retardation now living in community settings. To exemplify, from 1982 to 1987 the number of persons with profound mental retardation living in community settings increased by about 10,000 to an estimated 16,000. Of course, such movement was largely inevitable if deinstitutionalization were to continue, because by 1982, after years of selecting the least impaired public institution residents for release to community settings, institutional populations had become primarily composed of people with profound mental retardation and/or other severe impairments. Discharge of these individuals, once considered a "residual population," was the only way to continue the deinstitutionalization movement. Still documentation of this shift was an important finding of NMES. Despite these shifts large public institutions remained the typical residential experience for persons with profound mental retardation living outside their family home. Persons with profound mental retardation in public residential facilities

outnumbered persons with profound mental retardation in community facilities by more than 3 to 1. Still many thousands of individuals with profound mental retardation and/or other severe impairments living in the community settings are demonstrating on a daily basis the viability of community living for virtually all persons with mental retardation and related conditions, whatever the nature of those conditions and however severe they may be. Despite the rapid increase in community living opportunities for people with severe mental impairments about 91,000 people still live in large public institutions, almost all of whom have severe and/or multiple impairments. Continued deinstitutionalization will obviously require augmented services and technical and financial supports to assure that the needs of these individuals are responded to appropriately.

2. *The population of mental retardation facilities was overwhelmingly adult and is getting progressively older.*

In 1977 about 37.4% of persons in mental retardation facilities were 21 years or younger. By 1982 that proportion had decreased to 24.8%. Adjusted estimates from this study indicate that about 19% of persons in mental retardation facilities were 21 years or younger. At the other end of the life span there was an increasing number of older persons, increasing from 4.1% to 5.0% of residents being 63 or older from 1977 to 1982, to 5.5% being 65 or older in 1987. Similarly the middle-age bracket continued to grow, from 19.9% of all residents being 40-62 years in 1977, 23.3% being 40-62 years in 1982 and 27.5% being 40-64 years in 1987. These findings indicate first that efforts to ensure a place for children and youth with handicaps in our communities through a right to a free, appropriate public education and to some extent through various family support programs have had demonstrably positive effects on out-of-home placements of children and youth. At the same time the aging of the population in residential settings poses new challenges in assuring a system that provides age appropriate experiences for the people in that system. Nowhere is the challenge greater than for the growing number of people at or nearing senior citizen status. The proportion of mental retardation facility residents 65 years and older which has been growing steadily in recent years is likely to continue growing. In addition to increased longevity, major factors likely to contribute to sustaining this growth include the 8% of the residential population in 1987 between 55 and 64 years old, and federal policy that discourages placements of persons with mental retardation and related conditions into nursing homes, which in 1985 housed almost as many elderly people with mental retardation and related conditions (about 13,000) as did mental retardation facilities.

3. *Epilepsy, cerebral palsy and circulatory disorders were the most common secondary conditions of persons in mental retardation facilities.*

Epilepsy was reported for 30% of the mental retardation facility residents. It was highly related to the reported level of retardation (15% of persons with mild mental retardation, 45% for persons with profound mental retardation), and, therefore, to facility type. For example, 40% of large public facility residents and 20% of small facility residents had epilepsy, cerebral palsy was reported for 12% of residents of mental retardation

facilities, and was also associated with level of mental retardation (6% of persons with mild or moderate mental retardation, 20% of persons with profound mental retardation). Circulatory conditions were reported for 11% of mental retardation facility residents. These were most highly associated with age, being 4 times as prevalent among people 55 years or older than among younger residents. Controlling for age circulatory conditions were not associated with level of mental retardation. Clearly factors associated high probabilities of placement in institutional settings (e.g., the severest cognitive impairments and the oldest ages) are also associated with secondary conditions that must often be attended to in special ways. Increasing community living opportunities for persons currently institutionalized will also require attention to the secondary physical and health conditions they frequently experience.

4. *Institution residents were most likely to have functional limitations, but similarities across facility populations were as notable as the differences.*

A majority of residents of both small and large facilities, including large public facilities were reported to be able to use the toilet, get in and out of bed, feed themselves and walk across the room without difficulty or assistance. Independent toilet use was reported for 86% of small facility residents and 60% of all large facility residents, including 52% of large public facility residents. The ability to feed oneself without the assistance of another persons was reported for 91% of small facility residents and 72% of large facility residents, including 65% of large public facility residents. The ability to walk across a room without the assistance of another person (using equipment if necessary) was reported 92% of small facility residents and 73% of large facility residents, including 67% of large public facility residents. While the proportion of small facility residents reported to require personal supervision or assistance with bathing or dressing (43% and 37%, respectively) was considerably smaller than the proportion of large facility residents reported to require assistance (68% and 62%, respectively), the statistics may be most notable for the reported overlap of 75% in small and large facility populations in these gross measures of functional abilities. In other words, while for academic purposes institution and community facility populations may be judged statistically different in functional, self-care areas, for policy purposes the similarities between these populations are probably at least as significant as the differences.

5. *Large facility residents were considerably less likely than small facility residents to be involved "at all" in instrumental activities of daily living.*

Most instrumental activities of daily living are difficult for most persons with mental retardation and related conditions to perform. In four key instrumental activities (telephone use, money management, purchasing personal items and community travel by personal or public transportation) NMES confirmed this difficulty by showing less than 30% of sample to be able to perform even one of the four activities independently. While small facilities tended to have more residents who were judged independent in the instrumental activities surveyed, a more notable difference was in the proportion of residents who were not engaged at all in these activities, even with help. For example, in shopping for personal

items, 24% of small facility residents were not involved at all either independently or with help as compared with 55% of large facility residents, including 69% of large public facility residents. In getting around the community with personal or public transportation, 18% of small facility residents were not involved at all as compared with 46% of large facility residents, including 56% of large public facility residents. Small community facility residents were more often able to perform instrumental activities of daily living independently than were large facility residents. But when they were not, small community facilities were more likely than large facilities to involve residents in the activity by providing assistance and support.

6. *Prosthetic equipment used varied considerably by type of facility.*

There was wide variability in the use of various types of prosthetic equipment in facilities of different types. For example, corrective lenses were worn by 45% of small facility residents but only 25% of large facility residents, including 16% of large public facility residents. Hearing aids were worn by 6.5% of small facility residents and 2.5% of large facility residents. In contrast, wheelchairs were used by 23% of large facility residents and only 5% of small facility. Special dishes, cups and/or utensils were used by 18% of large facility residents and 6% of small facility residents. Urinary catheters and colostomy bags were used by only an estimated 1% of residents with no statistically significant difference by facility size or type. While it cannot be determined from the data provided whether the use of prosthetic equipment is appropriate, the magnitude of variation among different types of facilities is notable and could be in part associated with organizational factors as well as personal need. Assessment of the appropriateness of the use of various prosthetic devices particularly those affecting sensory acuity, mobility, and other important aspects of independent functioning, could make an important contribution to understanding the practical significance, if any, of the differences noted among facilities in the National Medical Expenditure Survey.

7. *Most people in mental facilities did not have jobs for which they were paid, although there were major differences by the place in which people lived.*

Only 39% of residents of mental retardation facilities were reported to have jobs for which they were paid. There was considerable variation by facility type, with 60% of small facility residents reported to have a paid job as compared with 30% of large facility residents, including 25% of large public facility residents. Over three-quarters of residents with jobs worked in sheltered workshops. Only 7% of residents had jobs in which they worked with nonhandicapped people. Supported or competitive employment away from the residential facility was reported for only 6% of small facility residents and 4% of large facility residents. Clearly in 1987 people with mental retardation and related conditions in residential settings were benefiting relatively infrequently from the growing efforts to encourage paid, productive activities for people with disabilities, particularly Integrated supported or competitive work. Efforts to improve opportunities for integrated, paid work for these populations seem needed, as do efforts to monitor their effects.

8. *There are more direct care full-time equivalent positions in mental retardation facilities than residents, more than 250,000 in all.*

Nationwide, there were an estimated 106 full-time equivalent direct care providers for every 100 residents of mental retardation facilities. Ratios of direct care staff members to residents were highest in large public facilities (1.51 to 1). Ratios in large facilities (1.18:1) were greater than in small facilities (0.72:1). Ratios of staff to residents were much lower in private for profit facilities (0.61:1) than in private nonprofit facilities, but much of this difference may come in foster family care homes where a single care provider provides care around the clock rather than in a time limited workday. With over 250,000 full-time equivalent direct care staff positions in residential services in the United States and estimated payroll expenditures of 5 billion dollars for staff filling those positions, clearly residential care is a major industry whose direct care work force is substantial in size and cost, and absolutely critical to its productive intent. Yet research shows clearly that major personnel problems abound. Staff turnover ranges on average from 25% to 33% in institutional settings, to 50% to 75% in community settings, higher than virtually any industry on which statistics are maintained. Low wages and benefits, nontraditional work schedules and job stress all contribute. Recruitment is becoming more difficult as the available pool of persons traditionally accepting these jobs (young adults, women) shrinks and is also recruited by a generally increasing service sector. Training becomes increasingly important as community services continue to decentralize services away from professionally dominated and supervised services. Clearly personnel initiatives are needed to guarantee basic stability and effectiveness in this industry as it continues to evolve toward community-based service delivery.

9. *Total ICF-MR participation remains highly concentrated in large facilities and increasing proportions of large facility capacity is ICF-MR certified.*

Medicaid participation in funding residential services for persons with mental retardation was highly concentrated in the large facilities. About 84% of all Medicaid certified capacity (ICF-MR, SNF, ICF) and 84% of ICF-MR certified capacity alone was in large facilities. Generally the smaller the facility the lower the likelihood that it would be certified for Medicaid participation. In 1987 facilities of 800 or more residents had 100% of their capacity certified; those with 300-799 residents were 96.6% certified; those with 76-299 residents were 66.9% certified; those with 16-75 residents were 31.3% certified; and facilities with 15 or fewer residents were 19.8% certified. Medicaid participation is in turn associated with higher levels of funding, higher ratios of staff to residents and specific standards for program content and review. Regarding funding, for example, nearly half (45.4%) of ICF-MR residents but only 11.7% of non-ICF-MR residents were in facilities with average daily costs of \$106 or more in 1987. In the area of direct care staff to resident ratios, ICF-MR ratios were twice as large as those of noncertified facilities (1.33:1 vs. 0.66:1). Clearly if this society's commitment to including people with disabilities in its communities is to be fulfilled, larger and more comprehensive programs are needed to provide federal participation in community residential services delivery.

10. *Occupancy of facilities was generally high and was related to both size and ICF-MR certification.*

Occupancy of mental retardation facilities was estimated to be 90.2% of the maintained capacity of facilities. Small facilities reported a 94.1% occupancy. Large facilities reported 89.8% occupancy. ICF-MR certified facilities had an occupancy of 92.0%. Noncertified facilities were 87.5% occupied. Small ICFs-MR reported only an 89.0% occupancy, while small noncertified facilities reported that they were 96.5% occupied. Large ICFs-MR were 92.5% occupied, while large noncertified facilities were only 79.8% occupied. Facilities with the lowest occupancy rates were large private, noncertified facilities (78.7% occupied), and the very largest facilities. Facilities with 800 or more residents had by far the lowest rate of occupancy (66.2%). The occupancy of large mental retardation facilities with ICF-MR certification was not only considerably higher than noncertified facilities, it was much more likely to be made up of persons with mental retardation and related conditions (96% of residents of large ICFs-MR and 75% of residents of other large facilities). While considerable attention has been given to the problems in the quality of programs in ICF-MR institutions in recent years, the quality of care in large noncertified facilities should be of equal or greater concern. With low occupancy, low staff to resident ratios (0.7:1 vs. 1.41 in large ICFs-MR), low per them payments (19% at \$81 a day or more vs. 70.5% of large ICFs-MR) and low federal involvement in program requirements and program monitoring, there seems reason to suspect that increased attention to the quality of these facilities is warranted.

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